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COPING WITH CANCER

A Resource for the Health Professional

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COPING WITH CANCER

A Resource for the Health Professional

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Foreword

With the publishing of *Coping with Cancer*, the National Cancer Institute reaffirms its continuing commitment to cancer patients and their families.

Due to improved treatment techniques, cancer, in many instances, can be considered a chronic disease, albeit one with a significant impact on patients and those close to them. Whether in remission or receiving treatment, those who are living with cancer deserve attention to their psychological, social, and economic needs.

Health communicators and planners along with direct caregivers play an important role in helping cancer patients and family members cope with the illness. The art of medicine, by definition, must attend to the quality of life as well as to its preservation. Members of the health professions are faced with the opportunity and responsibility for provision of the emotional support vital to patients and their families.

Coping with Cancer discusses responses to the disease, delineates known methods of support, and provides sources for additional information. With this background, caregivers can help patients and their family members to help themselves as they face one of life's most difficult experiences.

Director
National Cancer Institute

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I. Introduction

Coping with Cancer examines how patients and family members respond to the disease and, where feasible, suggests ways to identify and meet the needs of these people. The material is presented as a background for those unfamiliar with the psychosocial aspects of cancer, and as a reinforcement and reference for those dealing with cancer on a day-to-day basis. Health communicators and planners will find suggested approaches to total care of the patient, either by utilizing existing resources or by implementing programs developed by others.

For the purposes of this volume, coping is defined simply as adaptation under difficult circumstances, and includes any means used by cancer patients, their family members, and caregivers to deal with the psychological and physical threats imposed by cancer. A basic premise of this volume is that most cancer patients are essentially stable people who are dealing with a series of difficult situations. The concerns of those with mental problems which predate their disease or of those who develop severe disturbances while ill with cancer are not discussed.

This book concerns living with cancer, an area until recently often interpreted in the literature as preparation for death. While coping with the possibility of death as an eventual outcome of cancer is an important adaptive task, medicine is increasingly returning potentially cured cancer patients to society, and is often helping them function in their accustomed environments while they are receiving treatment. These facts have emphasized the need for a readjustment of focus to the patient and family who experience cancer as a chronic disease.

Still, concerns about mortality are part of living with cancer and should not be minimized. Clearly the prospect of a lifespan shortened by cancer is a major issue throughout the disease continuum. However, the purpose of this volume is to suggest that oftentimes death from the disease is not imminent and with this in mind, the task of the health professonal then becomes one of assisting patients and those close to them in living as fully as possible.

Coping with Cancer is a synthesis of information gathered from the behavioral sciences literature, as well as from medical sources. The rationale for such an interdisciplinary approach is simple: Any discussion of human behavior during illness must, of necessity, be placed in the context of human behavior in general. In addition, the psychosocial aspects of cancer have recently assumed more importance. The human being is now regarded as a person whose health depends on delicate interactions of organic, psychological, social, and cultural forces and not simply as an organism with biological disturbances. In other words, effective healing must consider the whole person and not confine itself to physiologic repair.

An interdisciplinary approach promotes the most complete understanding of the patient and his illness. The fields of medicine, nursing, psychology, and sociology combine—with no single discipline emphasized more than another—to examine how an individual maintains equilibrium in the face of illness, or if he is not succeeding, how his equilibrium can be restored.

The nature of this volume's source material varies in other respects: some sources are research studies with statistical analysis while others are in-depth examinations of participants' responses. Still other sources represent the clinical experiences of health professionals. These variations reflect the current state of the art; methodologies are not yet standardized and research results are supplemented with clinical impressions and documented anecdotal reports.

Acquainting readers with the psychological aspects of cancer by summarizing material from diverse sources admittedly does not provide the depth of knowledge wished by some. Those seeking more detailed information might turn to the references at the conclusion of the text, and to supplementary *Appendix C*. A separate bibliography is also available and can be ordered by completing the card located at the back of this book.

OVERVIEW

Coping with Cancer begins by briefly examining the dimensions of coping behavior as it occurs in daily life and during illness and suggests approaches used by cancer patients in adapting to their illness. Also addressed is the difficulty in determining the limits of coping behavior, i.e., when a patient response is adaptive and when it is maladaptive and the current lack of definitive evaluative criteria.

This volume is generally divided into discussions of cancer in the adult and cancer in the young. The divisions and the short discussion of Eric Erickson's stages of ego development are admittedly preliminary efforts to emphasize the unique considerations of cancer at various points in the life cycle and are intended to provide an impetus for development of a comprehensive model. Further subdivisions follow a disease continuum format, paralleling the available literature. While this is an accepted method of organizing material, it may deceptively indicate discrete psychological responses, neatly bounded by physical stages of the disease. Many concerns of patients and family members, however, are present throughout the course of cancer. These concerns, presented in Section 5, "Issues" (Chapter III, *Cancer in the Adult*), are touchstones for caregivers in offering emotional support, and should be considered in combination with the specific patient responses and suggestions for caregiver support delineated in the sections entitled Delay, Diagnosis, Surgery, Radiation Therapy, Chemotherapy, Remission and Recurrence, and Continuing Care.

Sections on coping by family members and health professionals emphasize the psychological impact of cancer on those close to the patient and present suggestions for alleviation of stress.

Information provided on financial aspects examines the costs of cancer to the nation and to the patient. The known status of cancer patients' employability and insurability is presented, along with general advice and guidance caregivers can offer those with cancer.

Completing the book are appendices containing specific sources of information for health professionals, including descriptions of current programs that promote coping behavior in cancer patients and families. Not every program is transferable to other hospitals or community settings, but each exemplifies a method of psychological support that may be beneficial to the health practitioner and planner.

II. Coping with Illness

Although later sections will address many aspects of coping with cancer in greater detail, the following discussion of coping with illness and general responses to cancer is intended as a framework for more specific issues.

Adaptation in response to illness consists of two general tasks: (1) coping with illness and its attendant problems, such as pain or paralysis, and (2) coping with life as it is altered by illness. Both tasks are faced not only by patients but by those close to patients as well, and can be further subdivided as follows:[151]

Illness-Related

(1) Dealing with pain and incapacitation;
(2) Dealing with the hospital environment and special treatment procedures;
(3) Developing adequate relationships with professional staff;

General

(4) Preserving a reasonable emotional balance;
(5) Preserving a satisfactory self-image;
(6) Preserving relationships with family and friends;
(7) Preparing for an uncertain future.

While the importance of these tasks differs according to the nature of the disease, the personality of the individual involved, and environmental circumstances, a variety of intellectual approaches and courses of action may be used to accomplish the tasks:[152]

- Denying or minimizing the seriousness of the illness. While appearing to be an evasion or self-delusion, this often provides time needed to assimilate the impact of the illness and to marshall resources and other coping skills to deal with the illness-imposed threat. The emotions engendered by the disease can be also denied or minimized.
- Suppressing, projecting (attributing to someone else), or displacing anger to a less threatening target (spouse rather than the physician) or to a more socially acceptable one (a healthy sibling rather than the sick child). Another skill in this category is the ability to isolate or disassociate one's emotions when dealing with a distressing situation. This detachment has a constructive value, often saving the individual from being overwhelmed.
- Finding a general purpose or pattern of meaning in the illness. This establishes a framework that makes individual events more manageable. The nature of this long-term perspective varies according to personal beliefs. For some, faith in a divine purpose offers consolation, while for others, the perspective is a highly individual construction.
- Rehearsing alternative outcomes of the illness. This is a form of mental preparation for any eventuality, and can encompass anticipatory mourning, in which death or other loss is acknowledged before the event occurs. This method often includes discussing possible outcomes with others and seeking additional information.

The following concrete courses of action undertaken by patients and family members not only assist them in accomplishing illness- and life-related tasks, but also give a sense of control over their situation:[152]

- Learning specific illness-related procedures, such as colostomy care, can provide a much-needed confirmation of personal ability. Performing the procedures successfully reinforces individual independence.
- Seeking relevant information or using intellectual resources effectively by learning about the illness and rationale for certain types of treatment is a common response. This intellectual mastery often provides a measure of control to those feeling helpless in their circumstances.

- Requesting reassurance and emotional support from family, friends, and medical staff usually involves an expression of emotion and can help alleviate tension. Comfort and reassurance may also be sought from support groups and self-help organizations. Patients who keep their feelings "bottled up" or who withdraw may need assistance in taking this step.
- Setting concrete limited goals, such as going back to work part-time or going away for a weekend, gives patients something to look forward to and a realistic chance of achieving something meaningful. Implicit in this action is the ability to break seemingly overwhelming problems into small, potentially manageable bits.

The coping tasks associated with an illness usually require use of the approaches and skills in some combination or sequence, and at various times in the course of disease. Information seeking, for example, may be important at the time of diagnosis, but may give way to rehearsing alternative outcomes as treatment progresses.[152]

RESPONSES TO CANCER

In an effort to ascertain how patients respond to a cancer diagnosis and meet the tasks imposed by the disease, researchers have attempted to find a pattern in the common emotional reactions reported by patients—anger, guilt, dependency, and denial among them. Generally, no consensus has been reached and methodological shortcomings, such as small sample size and the anecdotal nature of the data, have marred study findings.[242]

Efforts to differentiate between adaptive and maladaptive behavior have proven equally difficult, given the enormous variations in individual coping mechanisms and the vast spectrum of human behavior. When does behavior cease being healthily protective and start being destructive? How is one to judge when an individual's coping mechanism has become a harmful delusion? When does individual behavior become a barrier to complying with treatment? Research in this area has also been inconsistent and has produced little agreement about the prevalence of reactions (to specific life events like cancer), their sequence, or their duration.[242]

Yet answers to these questions could guide caregivers' interactions with patients and family members and assist them in establishing and maintaining relationships fostering acceptance and maintenance of treatment.

Attempts have been made to find patterns in patients' emotional responses, although concrete criteria applicable to every patient are not to be found in the literature. However, two authorities offer guidelines, different in focus and origin, that may be used to evaluate behavior.

The first approach defines a maladaptive reaction as the failure of the emergency responses (pain, fear, and rage) to protect the individual. Behavior changes from adaptive to maladaptive and requires caregivers' attention when one of the following conditions is present:[196]

(1) When the emotional reaction of a patient prevents him from seeking treatment, from cooperating with treatment, or interferes with treatment.

(2) When the patient's behavior causes more pain and distress than the disease itself or increases that which is present. This may be manifested by various physical complaints, or in difficult and uncooperative behavior with others.

(3) When the emotional responses interfere with everyday functions (such as work and interpersonal relations) or cause the individual to entirely give up his usual sources of gratification.

(4) When the emotional responses appear as conventional psychiatric symptoms. The patient may misinterpret his environment, including the people in it, in terms of his feelings and he may also suffer a considerable loss of self-esteem.

A second approach defines a maladaptive response through the Index of Vulnerability, which measures emotional distress and capacity to cope with current problems.[230] The Index is based on information collected from semi-structured interviews, in which thirteen types of patients' emotional and psychosocial distress are rated on a four-point scale. A high Index of Vulnerability indicates that a patient is not coping well and needs psychological intervention, while a low score indicates low stress.

Guided by this assessment of an individual's emotional state, caregivers can intervene to clarify predominant problems, give directions so patients can choose a course of action in solving problems, or allow patients to express their emotions and direct them to constructive channels.[230]

These two approaches to defining maladaptive behavior underscore the difficulty of making such a subjective judgment. General concepts formulated to embrace the behavior of all cancer patients remain just that—general concepts. Inherent individual variations are vital in determining maladaptive behavior, yet they make the judgmental task an enormously complicated procedure.

One investigator feels that researchers and practitioners should view coping as a *process* rather than a finite personality or character trait assessment.[121] More specifically, he feels that:

(1) Coping is a constellation comprised of many acts. It is therefore wise to observe and describe the many things a person does (or did) over the period of an encounter or encounters to adapt to a changing situation to determine how he has coped.

(2) As self-reported behavior is not always accurate, it is often wise to verify it with observer-based sources of information.

(3) Because coping is not a static state, but is rather an onging effort to make sense of what is happening, professionals should be aware of reactions and behaviors employed by the same persons in different situations necessitating adaptation.

Determining the spectrum of normal adaptive responses in patient and family members, as well as the range of maladaptive responses, is a major challenge to the behavioral sciences in their study of coping with cancer. More accurate definitions of reactive responses are needed, but at present, authorities agree that questions far exceed answers.[88]

III. Cancer in the Adult

1. LIFE CYCLE

In formulating a psychosocial profile of the adult cancer patient and those close to him, the caregiver might begin with the individual's position in the life cycle. Certain concerns, worries, and problems of the patient become understandable and, to some extent, manageable when seen in the light of his social and psychological age.

While agreeing on the existence of successive, distinctive personality changes in the mature adult (that is, postadolescent), psychologists have not yet formulated a developmental adult psychology similar to that for the childhood and adolescent portions of the life cycle. One reason may be the difficulties inherent in undertaking longitudinal studies examining the changes and issues that occupy men and women as they move from youth to adulthood to middle age to old age.[155]

A second reason is the greater complexity of the adult world, along with a greater variability of individual patterns in dealing with developmental tasks. Adults differ in the chronological age at which certain life events occur, while children are encountering similar developmental tasks at roughly the same chronological age.

For example, a familiar crisis point for adults is the departure of their children from home. This may occur when the parent is 40 and still struggling with a career, or at 65, concurrent with retirement. The nature of the individual's life outside the parental role and the manner of adaptation are quite different in each case.

A "stage" approach to the adult life cycle, then, should be flexible enough to allow for many variations:

> The idea of chronological aging (measuring one's age by the number of years one has lived) is a kind of myth. It is clear that there are great differences in the rates of physiological, chronological, psychological, and social aging within the person and from person to person. In fact, physiological indicators show a greater range from the mean in old age than in any other group, and this is true of personality as well. Older people actually become more diverse rather than more similar with advancing years. There are extraordinarily "young" 80-year-olds as well as "old" 80-year-olds. Chronological age, therefore, is a convenient but imprecise indicator of physical, mental, and emotional status.[31]

In 1950, psychoanalyst Erik Erikson formulated eight stages of ego development from infancy to old age. According to his theory, each stage is characterized by a central conflict; the resolution of the conflict determines the individual's future development, his success in adapting to internal and external demands, and his self-evaluation.[156] Erikson's last three divisions are the bases for this chapter's discussion of the young adult, the middle-aged person, and the older person.

The existence of other models examining adult development from cognitive, conceptual, intellectual, and ethical viewpoints is readily acknowledged, as is the need for a cohesive model summarizing the impact of illness at various points. Erikson's model has been chosen here for its simplicity and for its applicability to the conflicts created by cancer. The following, then, is offered as an interim tool for caregivers, and is an admittedly generalized representation of the adult life cycle.

One final observation is necessary before examining the life events common to each stage: not all people find the turning points of adulthood troublesome. Those who accept changes, including a diagnosis of cancer, with equanimity, who adapt gracefully, should not be overlooked.

THE YOUNG ADULT

To the young adult, life is full of choices. It is a time of many beginnings: field of endeavor, be it work or a continued academic career; marriage and children; a new home; and increased financial obligations and responsibilities. The young adult with cancer resents its effect on all these beginnings. Having just started a career or family, he must now add to his pressures all the problems of major disease. And financial considerations should not be underestimated; often the individual has little or no financial reserves for the costs of illness not covered by insurance or for income lost by disability.

Further, the young person is not accustomed to being sick. The lifelong experience of good health and energy imparts a sense of physical invulnerability to the young adult.[209] Suddenly an individual finds that he must carefully watch his physical well-being—something he probably has not given much attention to before.

Being sick then can be considered the loss of the previously healthy self, a loss that will be mourned. This mourning allows adjustment to the current situation and is necessary for realistic appraisals of the future.[209]

Erikson considers the central task of young adulthood to be the development of intimacy: "mutuality with a loved partner of the opposite sex with whom the individual is able to regulate the cycles of work, procreation, and recreation.[156] Cancer directly affects this task by altering family roles and relationships. If the patient is a wage earner, his partner may have to assume the total role. For those with children, child care must be arranged. The stress of cancer may have a tremendous impact on an established marriage, as well as a new relationship.

The unmarried cancer patient also faces major life rearrangements. It may be difficult or impossible to manage all the logistics of the illness unassisted, and help may be sought from friends or parents. This becomes particularly difficult for the young adult living some distance from his family. If assistance cannot be arranged, the patient may have to rejoin his immediate

To help their peers cope with financial and vocational situations, young patients in New York have formed "Living with Cancer, Inc."

family—a serious blow to the pride of the newly independent adult.

THE MIDDLE-AGED PERSON

Adjusting to a physically changed self is an important task in the middle years; those who are successful have rearranged their priorities and approach life from a wisdom-based perspective instead of relying on physical standards for self-definition and as the basis for meeting life's problems.[171] Successful adjustment will not totally obviate the stress of cancer, of course, but its absence may contribute to that stress.

Middle age makes heavy demands on an individual's emotional flexibility. The "empty nest" which occurs when children have grown and begun their own lives, the death of parents, and the death of peers are enormous changes. Successful adaptation requires emotional reinvestment in people or activities outside the family or sphere of close friends. Although they may not realize it, those in the middle years have a wide circle of community or work-related acquaintances from which to establish other relationship.[171] If an individual cannot establish alternative relationships or pursuits, a sense of loss, of life passing one by, may be magnified out of proportion to reality, creating a sense of isolation that cancer can only compound.

Erikson calls the need to expand horizons "generativity," or the "concern in establishing and guiding the next generation." [58] For example, men and women who have concentrated on careers or professional advancement may become more involved in civic improvement than in the past. For a woman whose primary concern has been rearing her children, the middle years represent an opportunity to develop broader means of expression and fulfillment, such as involvement in politics or community activities.

An individual who is not moving toward generativity, who cannot expand his horizons beyond the emotional and physical losses of the middle years, is obviously at a tremendous disadvantage in coping with a diagnosis of cancer. Unless the developmental tasks of middle age have been recognized and dealt with, the disease will reinforce the very fears uppermost in the patient's mind.

THE OLDER PERSON

Coming to terms with aging and with impending death are the psychosocial tasks of the older person. As one authority states: "It would appear that the elderly must resolve the issue of meaning in their lives as they approach death. Such is the coping task of the final epoch of life." [167]

As the prospect of death becomes more immediate, as friends, relatives, and the spouse die, the older person confronts the task of what Erikson calls ego integrity: "a basic acceptance of one's life as having been inevitable, appropriate, and meaningful." [58] This implies a contentment with one's life as it was lived, as opposed to despair because time is now too short for correcting past mistakes or starting anew. If the task has not been accomplished, contracting cancer may deepen the depression accompanying what is perceived to have been a meaningless life and may reinforce a sense that time is running out.

Retirement can be a significant loss; it represents the end of the role as the achieving wage earner—one highly prized by our society. Withdrawal from the work world is the loss of a previous standard of achievement, of a goal that no longer exists in the same form.[24] Too often, the retiree is no longer regarded by himself or others as an active contributor to society. Yet this is not always the case; retirement can also permit activities beyond the accustomed work role that can assure a continued, vital interest in living.[171] Also, older people are increasingly working part- or full-time well into their later years. Thus, cancer may be as disruptive of a professional life for them as it is for the young adult or middle-aged person.

Physical aging of the older person results in a significantly altered body image—impaired muscle tone, changes in bones, joints, and flesh, failing eyesight and hearing, and memory problems. To some, the "elder years seem to move in a decreasing spiral, centered around their growing preoccupation with the state of their bodies." [170] Others do not share this preoccupation and find satisfaction in human relationships and other activities transcending their physical decline. In either case, however, the physical effects of cancer and treatment may be difficult when combined with the other physical problems associated with aging.

2. DELAY

Even before their disease has been professionally diagnosed, some people may have noticed a physical symptom of their illness, and may suspect the possibility of cancer—especially if they recognize their symptom as one of the widely publicized warning signals. How people deal with their suspicion varies. Many seek medical confirmation; others wait. Because delay offers clues to the coping mechanisms cancer patients display in later stages of their disease, considerable research into who delays and why has been conducted. As a result, the delay phenomenon has received perhaps more than its share of attention. The literature is extensive, reaching back nearly a century. The varying definitions, criteria, and biases brought to each study make meaningful conclusions difficult. Nevertheless, some insights into individual cases may be offered by the viewpoints and speculations about delay.

"All of us in times of great stress need some minimal time to become mentally adjusted to misfortune, a sort of acclimatization period." [148] In other words, a certain amount of delay may be a normal part of a person's ability to adapt to stressful situations. Taken to the extreme, however, that self-defense mechanism becomes self-destructive:

> This period of delay permits adaptation to the threat and a realignment of defenses for coping with it. If the threat is too overwhelming, the period of delay may be so long that the patient's survival is actually endangered. Such cases are a victory for irrational expectation over both intelligence and the normal process of self-preservation.[21]

The question, then, is when does delay cease to be a normal reaction and begin to be a threat to the person's physical and mental well-being?

In 1938, delay was defined as a patient's failure to seek medical care within 3 months after recognizing medical symptoms. The time that elapsed beyond 3 months was thought to jeopardize the patient's health, and classified the individual as a "delayer" or "procrastinator." [110] Subsequent investigations used the 3-month guideline for statistical convenience and consistency.

In 1958, however, researchers found major difficulties in defining delay by an arbitrary, time-limited criterion. Consequently, they began to examine delay from the viewpoint of behavioral patterns, to allow for the response to all cancer types and sites by different population groups. Basic to this approach was the belief that different symptoms cause patients to seek medical assistance at varying rates.[100]

More recent work has followed up and expanded on the behavioral approach, to the point of abandoning the word "delay" as a pejorative term that "blames the patient or the doctor, without considering clinical, biological, or psychological factors." [240] The alternative term, "lagtime," is defined as the time between the patient's discovery of a cancer symptom and his request for medical evaluation.[240]

The concept of delay also includes "physician delay," or the time between a patient's first visit to the physician and the start of treatment. Physician delay is often due to accepted, valid medical procedures. A symptom may need to be watched for changes before deciding to undertake treatment, or it may be masquerading as another illness. The symptoms of stomach cancer, for example, might be confused with peptic ulcers, making diagnosis difficult. Physician delay also may be mingled with patient delay. Once the physician feels that a symptom warrants diagnosis or treatment, he may give the patient instructions for further action. The patient may not follow the instructions or may obey them at a later time.[10]

Another area of disagreement among investigators concerns the type of person who might be properly identified as a "delayer." Attempts to correlate socioeconomic and psychosocial characteristics with delay have, for the most part, proven inconclusive. In a 1953 study, no relationship was found between patients' educational level or previous experience with cancer (in a friend or family member) and reduction of delay time.[8] On the other hand, a 1958 study found delay to be "clearly associated with minimal educational attainment . . . [and also] a function of decreasing socioeconomic status." [109] A study conducted between 1968 and 1970 at a major urban hospital found that patients with better education and higher social class sought medical assistance sooner than the less privileged.[78] But in 1973, different investigators conducting research at the same hospital could not support those findings. The second study used personal interviews, supplemented by a battery of personality tests, to profile cancer patients with long lagtimes between discovering a symptom and seeking medical help.[240] Belonging to a lower socioeconomic group was not found to lengthen lagtime. Instead, other psychosocial characteristics shared by all delayers were discovered: "more denial, more entrenched belief that their condition was not serious, more marital problems, more frequent reports of isolation and rejection. A greater sense of powerlessness in the family of origin." [240]

When viewed as a whole, the literature does not single out one type of person or group of people as particularly prone to delay. The ascription of characteristics may be a useful beginning, but investigators do not concur on specific profiles.

Explanations of why people delay are equally inconclusive. For many, the bottom line of their procrastination is fear:

> When the first symptom is recognized, the patient immediately begins to anticipate what he thinks will happen to him during the treatment. This anticipation is based on the generally frightening ideas most people have about cancer. Often, the very recognition of the symptom can produce such acute anxiety that the patient delays going to a doctor.[21]

Rather than confirm what they fear, potential cancer patients frequently resort to a number of rationalizations: "It couldn't happen to me." "This could not be cancer because there has never been any cancer in my family." "I have done nothing to deserve this." [1] Perhaps they feel that overlooking or dismissing the symptom will somehow mitigate its consequences. In addition, the perceived social stigma of cancer may prevent acknowledgment of its presence, for fear of being labeled unclean, contagious, pitiable, or terminal.

Whatever the reasons for delaying, nearly everyone eventually seeks medical confirmation of symptoms. In a study of why people finally do end their delay, a change in the character or sensation of the still-unidentified cancer was found to be the most significant factor, with persuasion by relatives and the news of cancer surgery or death of a relative or friend next in importance.[3] This study also demonstrated that, even though a person may not be willing to take the initiative in asking for a medical opinion about a symptom suspected to be cancer, a face-to-face confrontation with the physician to discuss other matters may encourage discussion of the problem. A substantial portion of the patients under study came to a physician ostensibly for an unrelated complaint, or to accompany friends or relatives during their visits. At that time, the cancer symptoms were almost casually brought to the physician's attention. Perhaps these patients saw making an appointment to specifically ask about the suspicious symptoms as too deliberately admitting the possibility of cancer. As long as they were already in the office, asking one more question did not seem as threatening. In any event, the patients in this study stopped delaying when their need to know the truth, their need to relieve the symptoms, or their need to survive became greater than their need to delay.[3]

Once the delayer has sought medical confirmation of symptoms, caregivers should avoid expressing any disapproval of the patient's actions. Real or perceived disappointment will only add to the individual's existing burden of guilt. This is especially true for family members, who may feel responsible for not noting the symptoms more carefully or not insisting that the patient seek medical attention sooner.

In an effort to ingratiate themselves with physicians, patients will often confess their delay, recounting their thoughts and actions in detail. Calm acceptance of the facts is the most appropriate response for all caregivers, with reassurance that others have experienced the same difficulties. Such sympathetic acceptance will both allay the guilt of the moment and establish the foundation of relationships continuing throughout treatment.[1]

3. DIAGNOSIS

The cancer experience can be viewed as a sequence of related events proceeding from the first perception of a sign of illness, to hospitalization and treatment, and then to convalescence and cure, or to recurrence and death.[21] Diagnosis is the first intervention point in that sequence. The manner of communicating the diagnosis and the subsequent reactions of patient and family establish a pattern of coping and adaptation that continues throughout the disease. In fact, it can be accurately said that emotional rehabilitation should begin the day the patient is diagnosed.[175]

In today's age of specialized medicine, team treatment, and cancer centers, the physician conveying the diagnosis will probably not be the primary care physician throughout the disease. The family physician may arrive at and convey the diagnosis and then refer the patient to an oncologist or other specialist for treatment, perhaps at a larger hospital in another location. In a sense, this creates a larger burden for the family physician; not only must he communicate his own support in the most appropriate manner for the individual, but he must also build the patient's confidence in another, unknown physician. The specialist must then establish his own relationship with the patient before treatment.

Whether family physician or specialist, the primary care physician sets the tone for successful coping during the cancer patient's therapy, and must minimize the patient's anxiety, anger and depression while maximizing adaptive, realistic responses.[42] He need not hold the patient's hand at all times, but should recognize the moments when emotional support is as important as physical care. And diagnosis is one of those moments.

One way to avoid the devastating impact of a cancer diagnosis is to withhold the news from the patient, conveying only a broad notion of his condition. Contemporary physicians have inherited a tradition of nondisclosure; as recently as 1960 there was a strong tendency not to tell patients they had cancer.[160] A 1974 review of literature on the subject concluded that "the majority of doctors [prefer] to withhold information."[142] A common practice was to inform a family member, who would then take the responsibility of determining whether to tell the patient.

The "closed awareness" created when everyone but the patient knew his condition had consequences for all involved. Family members and health professionals were denied opportunities to directly express their concern and offer support to the patient. They were faced with the double strain of wanting to ease the patient's mind, but being forced to talk around the issue for fear of disclosing the diagnosis.[71]

The apparent protection afforded patients by closed awareness was an illusion, as the secrecy surrounding the diagnosis led them to suspect the worst. If they assumed a bad prognosis, they tried to conceal the knowledge to spare the feelings of their families and created yet another double strain of concealment.

A 1977 study of physicians' attitudes and practices concerning disclosure of a cancer diagnosis establishes a complete reversal of the previously noted trend to withhold the truth.[157] Ninety-eight percent of the survey respondents reported that telling the patient is their general policy. Physicians' responses to two other survey questions provide strong support for this policy. One hundred percent of the sample would prefer being told if they had cancer, and 100 percent felt it was the patient's right to know his diagnosis. The latter conviction is also held by patients. Studies of cancer patients who had been given their diagnosis have concluded that they prefer being told rather than being kept in ignorance.[142]

More complete revelation may be a function of the diminishing mystique surrounding cancer.[89] People are more sophisticated about the disease and willing to talk about it openly. Also, in keeping with nationwide consumer awareness, patients are likely to request information and accountability from those in authority, as evidenced by the Patient's Bill of Rights (*Appendix B*). For the contemporary physician, "an attitude of frankness feels right and, indeed, given the current disputatious atmosphere of medical practice, may be the safest one to adopt."[157]

THE PHYSICIAN

Diagnosis marks the start of the physician-patient relationship. Most patients view (and *need* to view) the physician, with his medical skills and experience, as their primary resource in confronting their disease. To them, he offers a shield against the confusion, helplessness, and fear that accompany a diagnosis of cancer. The patient needs assurance that the physician is competent, committed to the total use of his skills on the patient's behalf, and keenly aware of the difficult experience the patient is undergoing.[137] In fact, studies have shown that, aside from technical competence, the physician characteristic most important to patients is compassion. For some patients, lack of warmth and failure to demonstrate real concern are justifiable bases for changing physicians.[25]

The physician, then, must communicate his own confidence and compassion along with the content of the diagnosis. Determining how to tell and how much information to impart is the next crucial decision—one that is shaped by the physician's personal beliefs, medical school training, and clinical experience as well as by the individual situation of each patient.

Despite advances in treatment, the physician may view a diagnosis of cancer pessimistically. It has been suggested that pessimism is instilled in the physician during training and is reinforced by contact with older doctors. In one study, practicing physicians and students alike predicted a higher mortality rate at 5 years for certain patients than was actually the case.[50] Part of the reason for such pessimism may be that the medical student usually comes in contact with advanced or terminal cases during his training, and not with patients who might recover or have recovered. Moreover, the physician's understanding of cancer may be incomplete or fragmented because the disease is often studied on a site basis.[82]

Where it exists, such pessimism "can hardly *not* be conveyed to the patient." [89] Without knowing the basis for the physician's attitude, the patient may misread it as a specific response to the hopelessness of his case. As a result, he is deprived of any real hope that might be present.[177] At the same time, the physician must not encourage unrealistic expectations. Yielding to the patient's need for optimism, the physician may inadvertently make an unspoken promise that a permanent cure is only a matter of time. Instead, it has been suggested that the greatest contribution a physician can bring to the patient is a "rational view of cancer." Doing that may require the physician to readjust his own conception of the clinical and psychosocial aspects of cancer (see Chapter VI, *Coping by the Health Professional*, for further discussion.)

It appears from the 1977 study of physicians' attitudes and practices that the area of communicating with patients is receiving more emphasis in medical schools and hospital training programs.[157] Although instruction in communication influences the manner of imparting the diagnosis for some physicians, it cannot be assumed that the majority have (or had) access to such instruction.

While personal and emotional factors may well be the major determinants in physicians' decisions about how to communicate the diagnosis, guidelines gathered from the literature and the clinical experience of others may be useful to the physician.

Awareness of the patient's psychosocial background can assist the physician in planning his approach to the patient. However, time and logistics may limit what the physician knows about the patient, particularly if he has been referred from another physician or health care institution. Previous caregivers and members of the health care team who have worked with the patients and family, e.g., nurses, social workers, and mental health professionals, may be able to help provide information in the following areas:

(1) What the patient has been told about illness [168]
(2) What conclusions he has reached about the illness (including misconceptions) [168]
(3) Nature of the patient's family structure (to identify the family member or friend who will be most helpful to the patient) [32]
(4) Social and ethnic milieu of the patient (that determines confidence in physicians and acceptable ways of expressing emotion in stressful situations).[21]

Other factors reported by physicians that influence the manner of communicating the diagnosis are patients' age, intelligence, relatives' wishes about telling, and emotional stability.[157]

THE NURSE

Although the task of communicating the diagnosis generally falls to the physician, nurses have an important role in the process. Patients and family members frequently turn to nurses for supplementary information or interpretation of the physician's communication.[141] Thus, the physician must share with nurses the content of the diagnosis and the approach to the patient if they are to be an effective liaison between physician and patient. Oncology nursing specialists or other nurses may actually be present when the diagnosis is given and can begin to assess patient and family reactions and level of knowledge. If the diagnosis or certain aspects of it have been withheld and the nurse disagrees with this decision, her observation of patient and family reactions and capacity and/or desire for more information can be the basis for recommendations to the physician. Meeting with the physician about these observations will at the very least promote information sharing and can aid both nurses and physicians in their subsequent dealings with patients and families.[133]

INFORMING THE PATIENT

When giving the diagnosis, the physician must be sensitive to three aspects of the situation:

how and what to say; how to observe, listen, interpret, and better understand the patient's wants and needs; and how to convey his concern and support.

The discussion must be unhurried; enough time should be allowed for a careful explanation by the physician and corresponding questions by the patient. It must be undertaken in a place that ensures privacy, so the patient can express his true feelings without embarrassment.[89]

Including the spouse or close family member(s) can provide immediate reassurance and support for the patient. Information given by the physician can be assimilated by all those present and together the family and patient can ask questions.

The physician should carefully consider the language he uses in conveying the diagnosis.[87] There is still some disagreement about using the word "cancer," but above all, misunderstanding must be avoided. As explained by one patient who is also a psychologist:

> It is impossible to overemphasize the importance of selecting words that the patient will understand and that avoid the danger of setting up a negative image or expectation. Though I am strongly in favor of giving patients all the information they want, I am very much against the use of statements like "you have cancer" or "you have a 10 percent chance to live" without some understanding of how the patient will interpret them. To many, "cancer" means terminal illness and a protracted, painful death, with no hope of escaping the disease or its treatment. Specific, concrete descriptions of the condition (i.e., its stage and the treatments available) are less likely to be misunderstood or to leave patients to their fantasies about what the doctor really means.[68]

The question in conveying the diagnosis is not one of distorting the truth, but of determining what truthful aspects of the situaion will be most useful or least harmful to the patient. In this context, there is a need for sensitivity to the difference between the truth and the whole truth.[42] The physician should proceed tentatively, but honestly. The patient himself will provide clues to how much explanation is desired.[2] His capacity to assimilate knowledge will usually be indicated by myriad verbal and nonverbal signs. Long silences and avoidance of eye contact, for instance, may indicate that the patient has reached the limit of information that can or will be absorbed.

Some patients may bluntly ask, "Do I have cancer?" or state that they want to know everything about their condition. Others may clearly express their need to avoid hearing the diagnosis:

> One doctor told his patient that he had read the pathologist's report and knew the test results; the patient, however, replied forcibly, "Well, I don't want to know!" The doctor said: "You mean you don't want me to tell you?" The patient again replied emphatically: "That's right!" Another simply said: "If it's something bad, don't tell me." [85]

Extending hope appropriate to the circumstances is crucial and reinforces the patient's confidence in the care and support he will be receiving. False assurances are counterproductive and may erode the patient's confidence in the physician, but pointing out treatment alternatives and the longer remissions being achieved by modern medicine (if applicable) gives those with cancer the courage needed to cope with the disease. Family members, too, need expressions of hope to feel confident in the chosen treatment and to feel they can live with cancer.

Finally, patients and family members should be encouraged to ask questions and reassured that any other questions will be answered during the course of the disease.[101] They should be advised to write down questions prior to appointments. In addition, caregivers might consider taping conversations with patients and giving them the tape to replay at a less stressful time.[182]

THE PATIENT'S RESPONSE

Great care is required in communicating the diagnosis of cancer because of the tremendous impact the information has on those who have it. Regardless of how conscious the patient's suspicions of cancer, the actual news comes as a blow. Many patients liken being told their diagnosis to being "hit by a truck," [180] and report feeling "shocked," "terrified," "numb," "panicky," or "stunned." [22] Most of the patient's initial reactions protect the mind, offering time and space for it to adjust to the shock it has received. Just as the patient may have entertained a self-deception that allowed him to delay seeking diagnosis, so do some patients deny their cancer, even when unequivocally told by a physician. Without denial, these patients would be overwhelmed and faced with a crisis situation.[42] The more common alternative to total denial pertains to the ability to absorb the details and

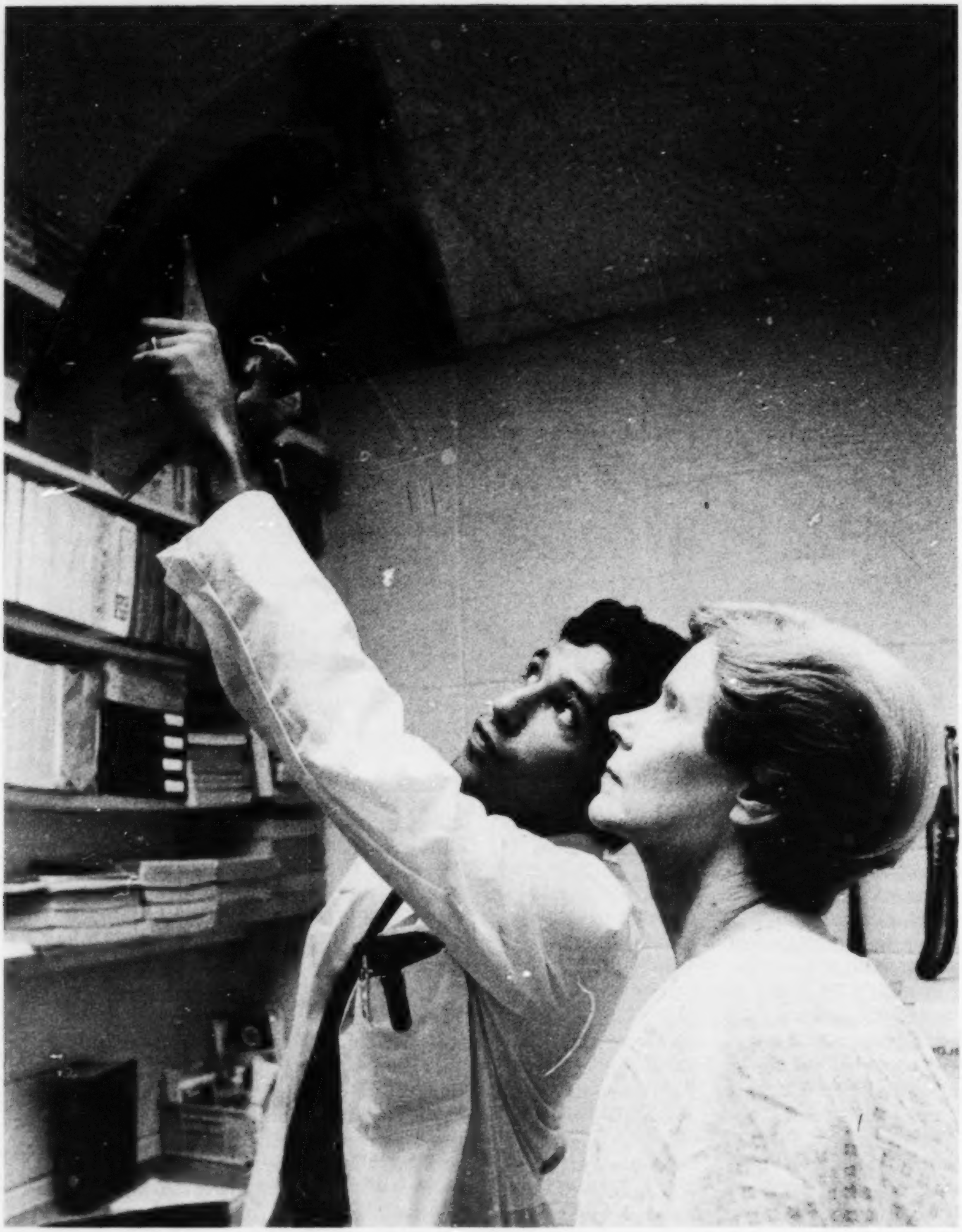
The impact of a cancer diagnosis prevents many patients from absorbing details. Caregivers should plan to repeat information about the disease and treatment in subsequent discussions.

implications of the diagnosis. Simply hearing the word "cancer" often prevents a patient from assimilating the complete diagnosis, indicated treatments, and possible prognosis. Therefore, caregivers must be prepared to repeat and elaborate upon information previously given to the patient and family.[12]

Caregivers should be prepared for expressions of strong emotion by the patient. Reactions that have been observed include anger, ranging from bitterness to open hostility. Anxiety is almost unavoidable and may be expressed by crying, or lack of concentration. Depression ("Why me?") is also a common response. Patients and family members need to be reassured that these feelings and actions are normal. Physicians and other caregivers should allow the open expression of emotions and fears without conveying disapproval.

Initial reactions may be closely followed by other approaches and courses of action, as outlined in the previous chapter, *Coping with Illness.*

Finding a general purpose or pattern of meaning was observed in over 90 percent of one study's patients, who "appeared to have a need for finding a cause . . . [and] referred to some past experience as responsible for their illness." [3] For these patents, the guilt seemed to derive from a common perception that cancer was "unclean," and a mark of disgrace.[3] Subsequent researchers have affirmed that patients tend either to blame themselves or to project responsibility for the disease onto some other person.[21] Though perhaps irrational, these feelings are prevalent and caregivers must accept their existence. Reassurance that the disease is not retribution for a perceived wrong doing is also necessary. Health professionals may find it easier to offer empathetic support if they realize



Some patients need detailed information about their disease and treatment in order to feel a sense of control over their situation.

the reason for their patients' feelings:

> When first confronted by serious illness, most people establish some sort of belief in order to explain what has happened, even if this belief is not expressed directly. . . . It is an attempt to find meaning and maintain mastery of an otherwise disordered, chaotic situation.[21]

Gaining intellectual mastery over the disease is a course of action taken by some patients. Increasingly, patients want to discuss and participate in decisions about their own treatment, as illustrated by the behavior of a librarian after being told she had cancer:

> She made a date for surgery and walked out of the office to think it over. She then proceeded to the library, took out all the latest journals in the field, and began reading the statistics about recovery, as well as information on the preferred surgical procedures.
> She called her physician in order to make an appointment to discuss this information and other details in the management of her case. He was quite blunt and asked her to leave these matters in his hands. She felt rebuffed and cancelled the surgery. . . . She insisted that while the surgeon might be an outstanding technician, he could not be her doctor because he didn't know how to deal with her.[104]

The lesson to be learned is obvious: The librarian's need to acquire information, to question and discuss her treatment was the cornerstone of her coping style. Denied this prerogative, she had to make other arrangements so she could continue dealing with the disease in her own way.

Those with cancer may seek basic information about the disease, types of treatment, effects of treatment, and prognosis. Patients can rely on multiple sources of information: materials received from the physician, books, journal and popular press articles, and even encyclopedias. To help them locate current, accurate information, caregivers can order *Coping with Cancer: An Annotated Bibliography of Public, Patient, and Professional Information and Education Materials* (see card at the back of this volume). Another source is the Cancer Information Service, a toll-free telephone inquiry system that provides information about cancer and cancer-related resources to patients, families, and health professionals, described in *Appendix D* "Telephone Information Services." They might also consult the National Cancer Institute and divisions of the American Cancer Society, both of which offer materials free of charge for patients and families.

Finally, caregivers can assist patients in informing others of the diagnosis. The patient may be reluctant to do this, especially if, as discussed above, he fears the disease carries some sort of social stigma. Education can help the patient correct his own misconceptions about cancer and prepare him to counter those raised by others. Caregivers should point out that the patient directs the course of such conversations. If he is open, candid, and reasonably composed in discussing cancer, friends and relatives are given an avenue for meaningful communication. Whether the option is exercised depends on the other person, of course, but patients should realize that they set the pace for communication, beginning at diagnosis and continuing throughout the illness.[80]

4. TREATMENT AND THE HEALTH CARE TEAM

Medical confirmation and communication of diagnosis bring the patient, family, and physician to consideration of treatment. Today, aggressive treatment often begins immediately after diagnosis. Whenever possible, however, it may be a good idea to wait a day or two before starting treatment or admitting the patient to the hospital. This allows the patient and family to absorb what they have been told and to prepare themselves mentally for what lies ahead. Elaborate explanations of the treatment and its side effects might also be delayed until the patient and his family are better able to handle them. At the time of diagnosis, it may be enough to simply outline what treatment seems indicated, answering any questions the patient and family might have. The primary care physician then can discuss complete details at a later meeting, preferably with the chemotherapist, surgeon, or radiotherapist also present.

The variety and complexity of available methods to treat cancer patients, while prolonging life, can also result in fragmentation of care.[108] In response to this changing character of cancer medicine, the concept of the health care team is assuming an increasingly prominent position in treatment provided by many research centers and hospitals.

Not only does the team concept bring together the variety of medical specialists involved in the patient's direct care, but also representatives of the psychosocial disciplines. Thus, the team approach can ensure integration of medical care for the patient and can address social and psychological needs. Regular review of an individual's progress and problems by those who deliver all types of care has several benefits for the patient and family members. They are guaranteed attention to a variety of needs by a wide range of caregivers, facilitating adjustment to treatment and resumption of life activities upon completion of treatment. When all disciplines are consulted in the initial assessment of the medical and psychological situation, potential problems can be identified and prevented or at least alleviated before developing into crises. Existing difficulties and solutions can be shared with all types of caregivers, providing a broad base of support for the patient and family. Also, the observations shared by team members form a comprehensive, ongoing measure of patient adaptation to the disease and treatment.

It has been said that the team approach can be of greatest assistance to the patient and family if one continuous caregiver contact is established and maintained. All members of the team will of course be involved in treatment and care, but if one professional is not designated as the primary patient contact, there can be strong negative consequences for those with cancer. For instance, one study of seven terminal patients who were seen by a different physician at each clinic visit found that they were afraid even to ask questions of a physician they did not know, and thus were denied opportunities for communicating difficulties and receiving support.[140]

Because this approach represents an excellent context from which to provide emotional support to patients and staff alike, and because a smoothly operating team is important for total care of the patient and family, a closer look at team composition, dynamics, and systems is useful to caregivers wishing to establish or to improve the existing operation of a team.

The exact composition of the health care team varies among hospitals and institutions, but members are generally drawn from the specialties of medicine, nursing, surgery, radiation, chemotherapy, psychiatry, psychology, and social work.[12]

Nurses in particular play a primary role in the health care team. Many nurses today have specialized in the care of cancer patients, and their clinical experience and knowledge are impressive. By education and intent, more than a few have immersed themselves in their helping roles, including consideration of the feelings of cancer patients and families.[18] Moreover, nurses are generally the most visible members of the health care team, a fact that lends them a distinct advantage when it comes to dealing with a cancer patient's emotional needs:

> So often patients turn to the person who is there, and that person is the nurse. Unlike most other disciplines, nurses are there on holidays, nights, and weekends. . . . The confidences they receive are amazing. It's not just the hearing that is so vital—it's the nurse's chance to learn, to mull over, to sort out.[18]

The inclusion of ancillary personnel, such as nurses' aides and volunteers, often gives the team new insights into a cancer patient's needs. They too see the patient frequently, and at times when he is more relaxed and less likely to be concerned about purely medical matters.[198] In addition, the team may call on dietitians, occupational therapists, physical therapists, and the clergy for support. Lay counselors, such as former cancer patients, may also be part of the team.

Most cancer diagnoses are made in general health care facilities. Because of financial constraints, the psychosocial resources of these institutions (especially the smaller ones) may be limited. As a result, the team approach to the "total" treatment of the cancer patient may not have been undertaken. Recently, however, some hospitals have instituted psychosocial training programs for existing staff members, such as nursing, social service, and pastoral care personnel. The trained staff members then work as a team with the primary care physician to ensure that all of the cancer patient's needs are met.

One such program involves staff members in a series of seminars dealing with the psychosocial aspects of cancer, including sexual difficulty, denial, and other responses to the disease.[224] In addition, a 20-week course trains one nurse on each unit of this oncology center to act as a psychosocial resource for other staff members. Finally, hospital and community nurses, social workers, clergy, and radiotherapy technicians are trained to lead peer groups of cancer patients and their families. This program calls on the services of a nearby psychiatric school to help design and conduct the courses and seminars. Similar assistance might be provided by in-house resources; for example, the hospital's psychiatric or social work service.

Once the team has been established in an institution, the key to its success is close and frequent communication. All information gathered about the patient's physical and emotional condition is shared among team members. And, in theory at least, traditional authority relationships are redefined, so each person's contribution to the patient's treatment is equally valuable.[108] However, one study of team dynamics warns that:

> Too often, interprofessional teams are battlegrounds for rivalous factions, struggling for power, speaking separate languages, or perhaps not speaking at all to teammates of other professions. Alternately, teams may be divided nations in which each profession conducts its function within its own territory, with communiqués taking the place of real communication and joint decision making.[96]

The study authors point out several ways to minimize such problems:[96]

- Selecting team members for their compatibility as well as their professional credentials;
- Limiting the size of the team to a nucleus just large enough to include all relevant skills, with additional support being called in as needed;
- Choosing team leaders on the basis of management ability rather than solely their professional ranking, or using coleaders;
- Establishing a process for decision making;
- Differentiating between decisions that should be made by the whole group (formulating policies and recruiting new team members), and technical decisions that should be made

Regular team conferences facilitate communication about each patient's care and contribute to good working relationships among professionals.

by members expert in the area under consideration;

- Avoiding the use of jargon peculiar to a specific profession.

Besides their daily interaction, team members usually meet at regular intervals (e.g., weekly) to discuss their patients and caregivers' own problems. The team conference may cover such matters as how the patient is responding to treatment physically and emotionally, what might be done to make him more comfortable, and whether the services of a certain member, such as the physical therapist or psychologist, are indicated. Because information relayed by the patient and family to one team member is communicated to everyone present at the meeting, team members have the chance to learn more about their patients than would be possible in the usual routine of medical care. Caregivers are assured a more complete view of the patient and can more easily structure their own approach. Keeping apprised of the patient's and family members' current situations at team conferences can save individual caregivers the time necessary to repeatedly ascertain the information.

The team conference also provides an opportunity for team members to support and encourage each other:

> One hour per week in conference saves many hours in terms of effecting harmonious inter-working relationships and keeping open channels of communication. Moreover, it enables all staff engaged in the care of the patient to acquire a better understanding of the dynamics of his behavior and that of his family. When understood, they become more acceptable and more manageable.[85]

5. ISSUES

In considering the patient's reaction to cancer, caregivers should bear in mind the emotional bases of behavior. From the time of diagnosis, the word "cancer" has elicited various responses from the patient as he attempts to cope with a possible threat to his life—especially life as he knew it before diagnosis. Understanding these responses is the first step in offering psychological support and guidance. Seemingly unusual, bizarre, or neurotic actions may be grounded in the reality of what it is like to have cancer and may be understandable when seen in that light.

The rigors of cancer treatment frequently confirm the patient's worst fears about what having cancer will mean to him and his family. In addition, treatment often raises new concerns that the patient must deal with. The director of a counseling center for people with life-threatening illnesses has observed that the concerns of cancer patients can be grouped under four general issues: alienation, mutilation, mortality, and vulnerability (or loss of control).[216] The significance of each issue depends on the individual and his ability to cope with it; most cancer patients confront them at one time or another during the course of the disease. Because these issues face the patient no matter what form of treatment he undertakes, they warrant an introduction here.

ALIENATION

When analyzing the attitudes of cancer patients, researchers have noted that fears of cancer and of death, although important to many patients, are often subordinate to fears of abandonment, unacceptability, and isolation. The latter two "can be greater sources of depression than fears of recurrence, and indeed some patients would prefer to die of cancer than face the issues." [214] Fear of abandonment is supported by an early study based on interviews with 100 cancer patients.[61] Besides noting the intensity of this fear, the study author also proposed that in their inability to conceptualize death, patients may equate death with abandonment.

In its extreme, this sense of alienation can lead to deep despair. One study of terminal cancer patients defined despair as "a bleak hopelessness over ever achieving any meaning, zest or validity in life."[124] Sixteen of the 18 study subjects suffered from despair and all described feeling alone, not relating to others, and being incapable of either love or hate. Furthermore, they failed to believe that any outside agent could help or that any action they could take would ease their loneliness.

The cancer patient's feelings of alienation frequently stem from the reactions of those around him. An article based on interviews with 38 patients, as well as medical researchers,

People with cancer can feel rejected, overprotected, and misunderstood all at the same time, even by members of their family.

psychiatrists, and surgeons, revealed that

> people who have cancer sometimes speak of themselves as the new lepers: of being rejected, overprotected, and misunderstood, all at the same time and by the very people they look to for support.[107]

According to the article, the emotional withdrawal of people close to the cancer patient is due to the belief that the patient will die. Friends and relatives may mourn the loss before it occurs, so it might not be felt so deeply when the patient actually dies.

Guilt, anger, and resentment toward the cancer patient may be manifested by a simple look, or even by hostile behavior. Husbands and wives may find other interests; friends may grow indifferent. Take the example of the patient

> who indicated that she rather dreaded going home because she expected the stream of visitors to be fatiguing. When she returned to the hospital several weeks later, she remarked quietly that "there were few visitors, many flowers and half-hearted telephone calls." [85]

The unfounded belief among the general public and even the patient's family that cancer is contagious may also result in ostracism. The evidence is anecdotal, but all too often patients report being forced to eat off paper plates to prevent contamination of dishes, spouses refusing to kiss or have other physical contact with their partners, and coworkers shunning the individual with cancer. Public education has repeatedly stressed that cancer is not contagious, but the belief may still persist. And its effects on the cancer patient are devastating.

To make matters worse, or more bewildering anyway, the patient may receive inconsistent signals from those close to him. Friends may not visit for weeks, only to reappear suddenly, more attentive and more affectionate than ever. People may offer support one moment and rejection the next. A woman participating in a support group for cancer patients related her daughter's remark: "Does your arm hurt, Mother? Well don't tell me if it does." Furthermore, recent research suggests that patients who can freely express their difficulties are especially likely to get negative reactions from others. Thus, those who are able to ask for help and to verbalize their problems are those least likely to get sympathy.[241]

If the patient's family, friends, and coworkers are not providing emotional support, there are alternate sources of help. It has been said that "no one understands what it's like to have cancer except another cancer patient." [165] Individual or group experiences with those in a similar situation have aided psychosocial adjustment of many cancer patients. Common problems can be shared and tips on day-to-day living exchanged. The patient may discover that other cancer patients have encountered rejection and avoidance. As a result, he may learn to attribute such reactions to attitudes about the disease and not to his own shortcomings as a person.[242] Programs involving former cancer patients as lay counselors and as adjuncts to the health care team are being developed across the country. For descriptions of programs using this valuable resource, see *Appendix A*, "Support Programs."

Social workers, visiting nurses, and the clergy might be called on as well. Their contact with other members of the community is an opportunity to eliminate the myths surrounding cancer and to suggest methods of assistance to friends or relatives.[85] Home visits by these caregivers can ascertain the patient's unmet needs, and ensure that the patient receives adequate medical attention and social support. For instance, caregivers might ask friends or relatives to look in regularly, and suggest ways for the family to assist the patient emotionally and physically.

When looking for ways to ease the cancer patient's loneliness, the health care team must recognize that it sometimes contributes to his emotional isolation. Patients in the hospital quickly come to know the ward's daily routine. They know when the physicians are making rounds and, thus, when they have been skipped. They may even know from the hospital page system when their physician is in the hospital and has not come to see them. And they know when the nurses are avoiding anything but the most basic attention to their medical needs. Outpatients similarly realize when they are being rushed through an office or a clinic visit. Whatever the reasons for such actions they can only increase the patient's sense of rejection. In response, one physician has made a point of visiting all his patients at least briefly during his hospital rounds.[185] Other health professionals might take his lead. The investment of time need not be great—a smile and a hello, an inquiry about how the patient can be made more comfortable, any genuine effort to let the patient know he is important and has not been forgotten.

Establishing an atmosphere of acceptance and understanding early in treatment, so that the patient feels he can openly share his problems, can go a long way toward counteracting fears about alienation. A psychiatrist suggests the following approach:

> Detach yourself from your technical viewpoint and try to place yourself in his situation, bearing in mind his knowledge of medical matters and his capacity for denial. Try to appear unhurried; force yourself to sit down to talk with him from time to time. Give him opportunities to talk and to ask questions.[26]

Particular care should be given to the way questions are answered. For example, the caregiver may think he is being kind by responding to the patient's questions with "You haven't a thing to worry about—you look just fine!" or "Why, you are just a gold brick—you'll be up in no time!" Actually, such responses suggest that the patient's worries are trifling and that the caregiver would not be affected by them if he were in a similar position.[20] As a result, the patient feels different and apart from "normal" people.

What the patient needs more than easy answers to hard questions is empathetic concern on the part of the health care team:

> We should let our patients know that we realize they are in a hard situation and that we feel for them. . . . Sometimes a simple remark, "It must be hard," or "I can see that this isn't easy for you" is sufficient, for this in no way robs the patient of his dignity—we are telling him he isn't a complainer, he isn't a bore, he is just a person in trouble.[20]

The health care team should also be alert to the patient's changing emotional needs and changing ways of expressing himself. Conversation should not be forced when the patient prefers to be alone. At times, simply sitting quietly with the patient can be more comforting than words: "You don't have to talk; you can watch television with the patient or have your coffee break by his bedside instead of in the lounge with your colleagues. Just let silence produce its magical effect." [92]

At other times, the patient may want to talk about something besides his illness. He may want to reminisce about happier times and about his past achievements. Such conversations help the patient reaffirm the meaning of his life and remind him of the people who fill it. Furthermore, the patient receives the compliment of knowing the health professional is interested in him as a person and not just as a disease.

MUTILATION

Related to the patient's sense of alienation are fears about mutilation as a result of surgery. The affected body part may represent a significant emotional investment for the patient:

> The lost eye, limb, or breast is often seen as part of a happier life; the possession of these organs was synonymous with belonging, activity, and worthwhileness—now irreparably impaired.[17]

Patients may experience insomnia, loss of appetite, difficulty in concentration, and disinterest in life as part of their grief for the lost organ.[17] Their perceived lack of wholeness may cause them to limit their work or other activities. They may withdraw from social and sexual relationships, fearing rejection because of their disfigurement.

Patients undergoing surgery for cancer require a great deal of reassurance and encouragement if they are to overcome their feelings about mutilation. The health care team should begin to work with the patient and his family before surgery and continue their emotional support throughout the postoperative hospital stay. Even if a good relationship between the patient and the team has been established preoperatively, it might break down after surgery, when the pain and disfigurement are fully realized. The medical care required for some postoperative wounds includes a frightening array of equipment, dressings, and laboratory tests. The patient and his family may not understand the need for such procedures, which they may see as inflicting additional and unnecessary suffering. And they may blame the health care team for mutilating the patient in the first place. Careful, confident explanations will help the patient and his family regain trust in the health care team.[93]

If the family appears supportive and able to cope with the situation, lengthy and frequent visits with the patient might be encouraged. The first night after surgery is often the most painful—emotionally and physically—for both the patient and his family. Allowing family members to take turns sitting with the patient, even if he is sleeping, provides the reassurance that someone will always be there if needed during the night. In addition, the patient may rest more comfortably knowing that someone close to him is nearby. Although the need for this kind of familial support is generally acknowledged for hospitalized children, it is often overlooked in the case of adult patients, whose maturity does not exempt them from fear and insecurity in a strange environment.

MORTALITY

Cancer precipitates an unavoidable confrontation with one's own mortality. Even where the prognosis suggests containment, and years of symptom-free remission are a reasonable expectation, death seems much closer than it was before cancer. A diagnosis of cancer raises not only fears of dying, but also concerns about the family's future. In response, the patient may devise elaborate fantasies and contingency plans. Most probably, he will start to put his public and personal affairs in order and begin a process of quiet farewells, just in case. Death is a possible outcome of cancer, and that fact must be faced:

> For the cancer patient, death is no longer an abstraction over which he philosophizes, but rather an uncomfortable reality which rides his back and creates a pervading feeling of dread.[100]

As discussed in *Chapter VI*, health care team members must come to terms with their own feelings about death and dying if they are to effectively help the patient cope with his. The team may want to explore this issue during its conferences, along with ethical questions concerning whether extraordinary measures should be used to prolong life and how much treatment should be undertaken in an attempt to save life.[190]

Most patients will have questions about their prognosis, and the health care team must answer them honestly, yet compassionately. Rather than evading the question or blurting out a blunt statement, one can say, "Things don't appear at all good," to relay the message.[26] Where therapy offers hope, that certainly must be conveyed to the patient. A physician wrote in 1789:

> It is a fact, that the desire for life is a very powerful stimulus in prolonging it, especially when that desire is supported by *hope*. . . . Despair of recovery is the beginning of death in all diseases.[187]

In the face of catastrophic illness, many patients find solace and strength in religion. Including the clergy on the health care team offers such patients a source of spiritual guidance, as well as someone who can help put their fears about death into the perspective of a religious philosophy.

Reflections on the body's mortality introduce fears of pain beyond endurance. Although the patient may never experience severe pain, "he believes that he will and he lives in the fear of that certainty." [190] Of course, drugs can relieve pain if it occurs, but they are potentially addictive—a fact that may be difficult for the patient and his family to accept. Weighed against the possibility of addiction must be the knowledge that, when pain is controlled, patients eat and sleep better, are less anxious about the onset of new pain, and have a generally more optimistic outlook.[19] Patients who are already taking medication for pain may be concerned about developing a tolerance that would limit the drug's future effectiveness. In addition, patients may have heard about or know of people who seem to derive no benefit from painkillers. These are realities that the patient and health care team must face together. Assurances should be given that many drugs are available and that, if one fails, others will be tried.

VULNERABILITY (LOSS OF CONTROL)

Illness in general and cancer in particular often elicit a sense of helplessness in patients that makes them feel controlled by external forces.[146] Some patients enjoy this dependency, relishing their moment at the center of family and health professional attention. But surrendering to the sick role, even temporarily, is difficult for individuals who value their independence. In a sense, the problem exists to some degree with all people: Human beings always exist in a social system, and a certain amount of dependence on other members of the system is inevitable. Nevertheless, sometimes that dependence is repugnant, especially when it is forced on the individual by illness. Particularly threatened are people whose self-esteem derives primarily from the role of caring for or supporting others. Homemakers and breadwinners with cancer may find themselves unable to perform their duties. As a result:

> Cancer in any of its many forms with the ensuing fatigue and debility often produces a sense of worthlessness among such patients [. . . for whom the need to be strong, to be independent, and to care for others comprises a permanent value system . . .] who find their life roles reversed as they become more dependent on others.[137]

The nature of cancer itself also contributes to loss of control. Uncertainty about the type and extent of treatment, as well as the duration of the disease, create an atmosphere of unending sickness. Further, there seems little the patient can do to stop the onslaught of cancer. Other diseases have concrete courses of action that, if followed, hasten recovery and prevent future illness. Heart disease, for example, can be controlled by medication, proper diet, regular exercise, and cessation of smoking. Cancer offers no comparable course of action.

Loss of control, then, refers to a lack of autonomy over one's life. The health care team can restore at least a portion of that autonomy by helping the patient assume as much responsibility for his own care as possible. Patients feel less dependent and more productive when they can do even simple things like shaving themselves, combing their own hair, walking to the bathroom, and feeding themselves. Beyond that, however, they may be willing and able actually to become part of the health care system.

With psychiatric consultation, a small cancer research unit successfully completed a patient health care study. At the beginning of the experiment, the medical staff largely viewed its patients as the "walking dead" and covertly ignored their emotional needs. In turn, the patients complained of "uncaring doctors" and "unavailable nurses." [103] As the experiment progressed, the unit was gradually reorganized. Patients were asked to make their own beds and to get their own water and ice. Nurses urged patients to take passes and leave the ward. Activities such as sewing and artwork were encouraged.

Surprisingly, most patients did not see these requests as further rejection of their needs. They quickly grasped the idea that they were being treated as functioning, useful, and responsible people. Patients coming back to the ward as their illness progressed after periods of remission at home experienced "a sense of relief at returning to a culture that treated them as though something was still expected of them." [103]

The study author believes the most important step taken was the communal dining room. With the cooperation of the hospital dietitians, who participated in all staff meetings, food trays were brought to a separate room where patients could eat together. This was described as a major breakthrough allowing lonely and isolated patients to talk with fellow patients. The communal dining room became the focus of other social activities, such as afternoon snacks and evening slide shows. There, "life was suddenly being lived." [103]

Restructuring the cancer ward may not be practical in all hospitals or for all patients. It does, however, illustrate what can be done when cancer patients are recognized as human beings—with human demands to be sure, but with counterbalancing human virtues as well:

> One can never stress enough to the health team that beneath every treatment or procedure there is a life which is loved by someone, a person of dignity and worth . . .[199]

6. SURGERY

For many types of cancer, surgery represents the primary and most effective treatment. However, patients often react to the prospect of surgery with great apprehension, and may be angry, resentful, depressed, anxious even panicked about the operation.[22] The basis for these reactions can often be found in the patient's fear of death from the surgery or anesthesia and fear of the resultant pain or mutilation.

Despite advances that have made such deaths rare, many people fear they will die on the operating table:

> Far more frequently than is realized by physicians who are professionally immunized to the impact of surgery on others, patients regard operations with active dread. They are far from sure of survival. They feel they have only a 50-50 chance.[22]

In addition, some patients are apprehensive about anesthesia and the loss of consciousness, which many equate with helplessness and surrender to a potentially harmful situation. They fear they may not awaken at all, or that they will suffer postanesthetic side effects, such as nausea, vomiting, or dizziness from which they may not be strong enough to recover. They also fear waking to unbearable pain and to the discovery that their bodies have been irreparably damaged.

The patient's anxiety about his impending surgery is often revealed in vivid dreams and nightmares. In these dreams, patients frequently visualize their mutilated bodies or organs, their death or funeral, and even appeal to their parents for protection—even though the patients themselves may be in their 60's or 70's.[214]

Fears and misconceptions about surgery may be influenced by the opinions and experiences of others close to the patient. According to one study, patients expect fates similar to those of their relatives or friends—especially if the outcome of their surgery was unfortunate.[23] The patient's own experience with surgery also affects his preoperative outlook and, eventually, recovery; if previous operations

Periodic visits by physicians during hospitalization ease a patient's fears and help dispel misconceptions about surgery.

were difficult, he is apt to encounter problems again.[23] Other concerns, such as financial worries or family frictions, also contribute to the patient's anxiety.

Some preoperative fear is normal and even desirable because it stimulates the patient to take the medical procedures seriously and to make realistic plans for coping with it.[94] In fact, patients who are abnormally calm may be masking their fears.[215] Such patients may have unrealistically optimistic expectations about the outcome of surgery, and when those expectations are not fulfilled, depression and other emotional complications are likely to occur.[23]

Caregivers can ascertain the patient's fears, family problems, and misconceptions about the operation by questions interspersed in a preoperative discussion about the surgery and its probable effects on the patient.[161] Being aware of impending pain, discomfort, or bodily changes before the actual event allows patients time

> to start working through their fears and anxieties, to rehearse new strategies, and especially to find out what they themselves can do and what the medical staff can contribute. . . . The absence of mental rehearsal for impending dangers can lead to feelings of helplessness when the danger does materialize, to disappointment in the physician and hospital staff, and to an increased vulnerability to stress.[94]

Furthermore, preoperative counseling may reduce certain surgical complications. In a study examining the effects of encouragement and formal education, surgical patients were visited by an anesthetist the night before their operation. At that time, the anesthetist explained what they could expect in the way of postoperative pain; "they were then taught how to relax, how to take deep breaths and how to move so they would remain more comfortable after the operation." [53] Compared with a control group of patients who did not receive this special care, the "educated" patients required half as much postoperative narcotics and were able to go home more than two days earlier than their less-informed counterparts.[58]

Although the anesthetist and other members of the health care team, such as the nurse, can provide valuable and essential support, most authorities agree that the surgeon should be the primary communication link. Even if they have been referred by another physician, patients who are to undergo surgery regard their surgeons as the best source of information about the operation:

> The surgical patient's anxiety has its roots in his proposed operation. To relieve this anxiety, to feel "safe" and "secure," his transference toward his surgeon will be like hero worship. Behind the role the surgeon plays in the patient's fantasy life . . . lies the key to the patient's preoperative and postoperative behavior.[184]

For patients who are especially anxious, the surgeon's preoperative discussion should take place in several visits, giving a small amount of information each time. Family members or close friends might be included to lessen anxiety and reinforce the information provided. The discussion should include how long the patient will be in the hospital and the outlook for convalescence and recovery.[204] This will enable the patient and family to make practical arrangements concerning such matters as care of children, and absence from work.

At some time when the patient is not present, family and friends might be questioned about their beliefs concerning surgery and cancer. Explanations to counter misconceptions may be in order. In any event, they should be warned not to alarm the patient with "frightening stories about similar surgery performed years ago on someone else they knew—or even with the best intentions—discussing his [the patient's plight] with him in a fearful way." [184]

Once the surgery is over and the patient realizes that he has come through it, the process of coping with the injury to the body begins. Discussion about the extent of surgery and the biopsy results should wait until the patient has recovered from the effects of anesthesia and the surgeon or referring physician has the time for an adequate explanation. The patient's most immediate concerns will be whether he definitely has cancer and whether the operation "got it all." A realistic approach should offer hope for control of the cancer, rather than cure.[210]

Next, the patient will probably want to know exactly what damage has been done to his body. Some patients, however, prefer to delay that knowledge for a while, particularly if the surgery had a potential for permanently altering the body's function or appearance. For example, many mastectomy patients consciously refuse to accept the loss of a breast for several days and sometimes weeks after surgery, "a defensive maneuver that should be respected by hospital personnel." [22] One study of 21 women post mastectomy found that the real impact of the surgical experience did not occur until the woman returned home from the hospital.[176] Similar reactions might be expected from amputees or people undergoing extensive head and neck surgery.

The patient's ability to cope with the physical effects of surgery is largely determined by the meaning the affected body part or organ has for him. Surgery involving removal of bone and muscle, followed by residual skin grafting, may leave scars that are not easily concealed with clothing or makeup, even after plastic surgery. Such scars mark the patient for every social encounter and affect his perception of himself as socially acceptable and sexually desirable. In the case of cancer surgery resulting in an ostomy for the evacuation of wastes:

> For some patients, excessive cleanliness has always been the criterion for acceptability to others. Disruption of this defense . . . causes a withdrawal from participation in family activities even when acceptance and support exist.[215]

If surgery means the patient cannot continue working or maintain his preoperative level of productivity, he may fear loss of status in the family. Previously independent people may worry that their increased physical dependence will be an intolerable burden to those around them. And, "even if not expressed, the conviction is that a 'deformed' or 'disfigured' person is held in very low esteem by the community at large." [22]

When the patient is unable to fully accept the change in his body after surgery and fails to make the necessary compensations, conflict arises between the way the body actually looks and the way the person pictures his body mentally. This is a form of denial, and is usually followed by some modified recognition of reality, grieving for the lost part or function, and depression, with accompanying emotional and physical symptoms. An example of a patient's inability to adjust to amputation of his leg is found in a study of depressive reactions associated with surgery for cancer:

> Before the operation [the patient] had been extremely active physically, priding himself on his athletic prowess. Immediately postoperatively he became overly cheerful, if not definitely elated, and clambered around his small sailboat with the aid of crutches. The period of elation was terminated abruptly 3 weeks postoperatively when he slipped and fell. He immediately broke into uncontrollable sobbing and at that instant developed a phantom limb. The phantom limb and severe depression have persisted to the present time.[214]

Patients who attach great psychological significance to the lost organ may believe the surgery has somehow compromised the body's internal structure and may complain of weakness and frailty that have no physiological basis. Psychosomatic symptoms may also be present. After a hysterectomy, one woman reported an increase in appetite because "I feel an emptiness —a space here in my stomach. Something is missing and I eat so much to try to fill up the emptiness." [48] These patients frequently restrict their sexual and physical activities, believing their bodies are now especially vulnerable—despite reassurances to the contrary from the physician. This behavior may persist for an extended period following the operation. In a followup study conducted 5 to 10 years after colostomy, patients reported a sense of physical fragility and weakness, and activities requiring mobility and expenditure of energy were reduced, sometimes drastically.[162]

The retreat from function results from an inability to master the problems created by the traumatic event; functions are resumed when the problems are solved. If the problems derive from the perceived and real physical limitations after surgery, their solution requires a major effort to construct alternatives or compensating patterns that address the needs formerly satisfied by the lost activity. The health care team can assist the patient in this adaptation process by continuing the emotional support and educational efforts it began preoperatively. Here, nurses, physical therapists, social workers, and other team members assume increasing importance in helping the patient realize the options open to him. Furthermore, the physician has a unique opportunity to strengthen the patient-physician relationship while the patient is still in the hospital:

> It is in this period more than in any other that he becomes the healing physician, the helper of the wounded, the encourager, and the resolver of doubts. . . . His mission is now entirely devoted to healing in its historical and generally understood sense.[22]

Daily visits to change dressings and examine the wound provide a relaxed atmosphere for casual conversations about the patient's adjustment to surgery.

Hospital personnel should also be aware of two seemingly negative postoperative emotional responses that may actually be positive signals of the patient's eventual good adjustment to surgery. These are the patient's increased demands and expressions of anger and resentment. Trying as they may be for the hospital staff, postoperative demands may be requests for support. "As a matter of fact, self-reliant patients can constitute a greater problem, since they may be completely unable to notify others of their emotional plight or turn to others when in trouble." [22] Similarly, expressions of anger and resentment, within reasonable limits, are normal reactions to injury, and should be viewed as possible signs of recovery. Someone who readily submits to hospital routines will likely be viewed as a good patient. However, his primary problems of staying in touch with his feelings and contending with his legitimate fears are not necessarily solved by such submission.

Another factor in the patient's response to surgery and to cancer is the environment of the hospital itself. Hospital staffs are becoming aware that routine elements of hospital life are unsettling to the patient who is trying to discover and adjust to his role. Often without previous surgical experience, he may be disturbed by such basics as hospital rounds and consultation with residents, interns, and specialists. The cancer patient may still be in an early stage of shock and denial, and anxious about the confirmation or the extent of his disease. A casual, offhand, or overheard remark from an unknown physician might shatter his carefully constructed defenses.

A patient harboring notions of guilt about his condition may see the hospital—with its colorless corridors, uniformed attendants, and often impersonal human contact—as a place of confinement. Sometimes guilt prompted by religious or moral attitudes may lead to perception of the surgery as punishment.[26] Such feelings go deeper than the hospital environment for their source. Nevertheless, personalized intervention by the hospital staff can go a long way toward easing the patient's concerns about the hospital and his place in it. Hospital staff members should try to "increase their awareness of the potential environmental hazards and . . . enhance [their] ability to empathize with patients, i.e., to recognize the meaning of the hospital situation for them." [108]

Health care providers sometimes make the mistaken assumption that, once the patient is discharged to the care of the family, he will receive the attention and support he needs at home. In reality, however, some patients dread their release from the hospital nearly as much as their admission to it. Some patients come to accept and depend on the hospital and sick role for a sense of security, particularly if their home environment is unstable. According to one study, the nature and quality of postoperative care is determined by the preoperative family relationships.[49] If the patient's home environment was supportive before the operation, it will probably remain supportive postoperatively. But previously poor communications and strained relationships will usually worsen after surgery. Whether the patient is able to adjust to his altered appearance or increased dependence is largely determined by the family's acceptance of those same issues. If the patient feels rejected at home, he may fear the rest of society will also reject him. Thus, he may avoid resuming social relationships or returning to work.

Before discharge, caregivers should assess the patient's family situation.[168] Communication with the family since onset of illness can be reviewed and members of the health care team consulted for their evaluations of the family's ability to care for the patient. Home care by private or visiting nurses or admission to an extended care facility may be necessary once the patient leaves the hospital. If family members are experiencing emotional difficulties and communication problems, caregivers might consider referral to family therapy (see *Chapter V*, "Coping by the Family"), or a family support group (see *Appendix A*, "Support Programs"). Patients who live alone and have no friends or relatives nearby to care for them may require similar assistance in the transition from hospital to home.

The surgical experience can be distressing to all patients, but intervention by caregivers pre- and postoperatively can effectively reduce the anxiety. A cancer surgeon expressed this point of view to his colleagues:

> The modern surgeon who is genuinely interested in giving patients with cancer the most effective treatment possible should possess, in addition to surgical knowledge and skill, a familiarity not only with the uses and limitations of radiotherapy and chemotherapy, but also with the more common psychological problems with which these patients are confronted. An understanding of even the elementary principles of psychotherapy would help us to make better use of that nebulous quality called the "art of medicine" and thus to afford patients with cancer better overall treatment.[210]

7. RADIATION THERAPY

Of all treatment forms, radiation therapy seems particularly associated with misconceptions, misunderstandings, and apprehension.[186] The prospect of receiving an invisible treatment from a large machine in a room with no other human being present is understandably frightening to patients and family members. Thus, the increasing use of radiation—as a primary treatment, in combination with surgery or chemotherapy, or as a palliative measure—calls for special attention to the cancer patient's perception of this therapy.

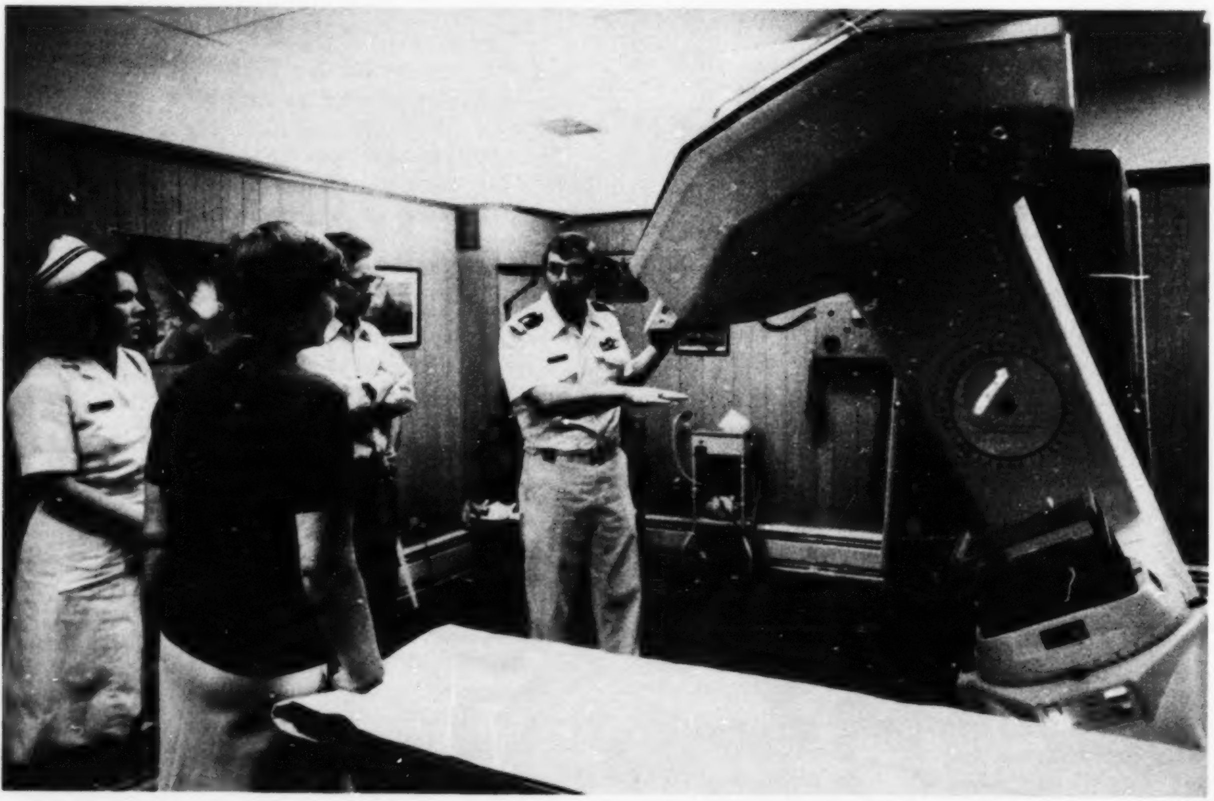
The basic principles are simple: External treatment uses x-rays, radium, and other sources of ionizing radiation for the destruction of cancerous cells. The tumor is encompassed within the field of radiation at doses that will destroy the cancer, yet have a minimal effect on the surrounding normal tissues. Other types of treatment are indicated if surrounding tissues will be substantially harmed or destroyed.[202] With internal radiation, an isotope is placed in a body cavity, directly into the cancerous tissue, or into the system to treat cancer from within the body.[56]

On hearing they are to undergo radiation therapy, patients are subject to a variety of concerns. It may activate or, in the case of patients who have already undergone surgery, reactivate fears about death and dying.[186] To many, it means that surgery did not eradicate the cancer and implies advanced or particularly virulent disease. In addition, the prospect of radiation therapy may arouse concern about carcinogenic effects: Will the radiation itself cause cancer?[170] It may also elicit fear of being burned or disfigured and being unable to perform normal body functions. The size and nature of the machinery used, the invisible character of the treatment, the development of physical side effects, and concern about loss of sexual function and sterility all contribute to psychosocial difficulties as well.

Family misconceptions may include the feeling that radiation therapy is a futile procedure in a hopeless situation.[186] In addition, some family members avoid contact with the patient, believing that he has become radioactive and contaminated. Obviously, such an attitude can heighten a cancer patient's sense of alienation or, carried to the extreme, abandonment.

Misunderstandings about radiation may stem from a lack of information or from distorted explanations given by relatives and friends. It cannot be assumed that the referring physician explained the therapy and side effects. In fact, 52 percent of the patients in one study said they "remembered receiving *no* helpful information about their upcoming treatment from the referring physician."[149]

An assessment of the patient's knowledge about the disease and radiation therapy before treatment may be helpful to caregivers. Physicians at one health care facility have developed a written interview that can be used during the initial physical examination. If combined with psychological tests, the interview can provide information about habitual responses to anxiety and can assess real and imagined knowledge about the disease and treatment.[186]



Patients and family members can be prepared for radiation therapy by familiarizing them with the machinery before treatment begins.

Data gathered from the instrument can assist the radiotherapist in judging the appropriate amount and presentation of information to the patient at their first meeting. It may be necessary, for example, to reexplain the diagnosis or to discuss the patient's prognosis. Inclusion of family members in this and subsequent consultations is important to dispel their misconceptions, to share care information, and to provide patient support. Spouses especially should be included when loss of sexual function or sexual attractiveness because of treatment is feared. Referral to sexual counseling also may be indicated.

Although the subject matter of the first meeting will vary somewhat according to individual circumstances, certain issues bear mentioning here. The reasons for radiation therapy should be detailed for each case, including whether the object is cure, local control, or pain control. Potential positive results should be stressed, giving the patient hope for control of the disease without compromising realistic expectations. The duration of therapy, as well as the need for additional radiation treatments, should be discussed. Reassurances might also be given that modern equipment and techniques minimize the risks and side effects of radiation therapy, and the healthy tissues and organs are less likely to be damaged because the cancer site can now be located with pinpoint accuracy. Finally, caregivers should explain that the machines are fully shielded so there is little chance for radiation leakage.

The function and mechanism of the machinery might also be mentioned. A brief tour of the treatment area to illustrate the explanation may alleviate some of the fears associated with the equipment. As many patients are alarmed by the size of the machinery, staff members might consider decorating the room with large murals and photographs to make the units appear smaller.[163]

Topics explored at the initial meeting can be supplemented with written materials for future reference. Some health care facilities are experimenting with additional means of communicating information, such as placing audiovisual presentations or simple explanatory posters in waiting rooms and treatment areas.

As in other aspects of cancer care, information given at the initial discussion with the patient and family may be forgotten or misinterpreted. Opportunities for repetition and subsequent visits should be provided throughout the course of treatment.[186]

In addition to counseling the patient and family before treatment, nurses can reinforce the radiotherapist's explanation, establish a rapport for future support, and give specific information about logistics and department routines. Other points of explanation might include the following:[159]

(1) The radiotherapist may mark the treatment portal with indelible ink (or gentian violet), which the patient is not to wash off.

(2) The patient should feel no sensation during the treatment.

(3) Although treatment time seems long, it is actually a brief period, for example, 1½ minutes with the linear accelerator.

(4) The radiotherapy staff will position the patient for treatment but will leave the room during actual treatment time. There is a closed circuit TV or a viewing window and communication system for patient-staff interaction during actual treatment time.

(5) The patient must maintain the position he or she is placed in and lie absolutely still during treatment.

(6) After treatment the patient is not radioactive.

At some point in the treatment process, caregivers will need to know the patient's home situation to determine apparent or expected problems, such as financial status and ability of family members to care for the patient. When radiotherapy is administered on an outpatient basis, transportation may be a concern. Health care providers might refer patients to the local chapter of the American Cancer Society, which may have volunteer drivers or reduced fare arrangements with local taxi companies. Patients coming to the hospital from other areas may need lodging for the period of outpatient treatment. The situation varies in different care settings: Some have homes or hostels for patient use and some have negotiated reduced rates at local hotels. If neither is available, the Department of Social Services may be able to suggest moderately priced accommodations.

Deciding when and how much information about side effects should be given to the patient and family is difficult. Yet the results of one study, based on interviews with 50 patients, indicate the need for a complete explanation.[170] The study showed patients who had been warned before treatment appreciated the information and praised their physicians. More significantly, none complained that the physician had warned him of a side effect that did not materialize. This may be a function of selective memory; information about unexperienced side effects may have been quickly forgotten. But patients who had not been warned of side effects that occurred were "disappointed and angry," and had difficulty accepting their physicians' subsequent explanations.

It appears that advance discussion of side effects is desirable. Certain site-specific reactions to therapy *must* be discussed before treatment, giving patients time to adapt and take compensatory action. If a patient is aware that head and neck irradiation is expected to cause hair loss, for example, a wig or toupee can be selected and purchased. In males, radiation to reproductive organs can inhibit sperm production or result in permanent sterility (depending on the dose); men facing this possibility may wish to investigate sperm banks. Radiotherapy to the female reproductive system can reduce or abolish ovarian hormone production, leading to temporary or permanent menopause. Loss of capacity to bear children can have enormous psychological consequences that may indicate referral for counseling. Patients who are to receive abdominal radiation should be warned about possible nausea and vomiting, and should be assured that medications are available to control these side effects.

With all patients, a clear distinction should be made between site-specific reactions and general side effects to correct common misconceptions; for instance, that radiation to any area of body will produce nausea and vomiting. Family members also must be educated about possible side effects and patient care during and after treatments and reassured that symptoms can be controlled.

This task often falls to the nurse, who can increase the patient's and family members' retention of care information by communicating the rationale for care guidelines. For instance, explaining that irradiated skin is sensitive and must be protected from irritation gives an easily-remembered reason for keeping sun, heat, and tight clothing away from the treatment area.[159]

Enlisting the cooperation of the family can also help maintain the patient's nutrition, important for increased tolerance to therapy. Adequate protein and calorie intake can decrease nausea and vomiting (if experienced), reduce or eliminate the need to interrupt treatment, and enhance the body's immune system. More important, a well-nourished patient feels better and is more active.[183] Eating properly may be a problem for patients experiencing anorexia, changes in taste sensation, or dry mouth as a result of head and neck irradiation. Booklets addressing these difficulties, with information on diets and nutritional supplements, may greatly aid in food preparation for the patient.[5]

The emotional difficulties of radiotherapy patients may be alleviated by several members of the health care team. Although the radiation oncologist may be interested in the emotional as well as the physical side effects of the treatment he has prescribed, patients do not necessarily view him as a source of nonmedical support. They may feel he is too busy to approach or that their treatment would suffer if time were spent by the treating physician on other problems.[149] Nurses, on the other hand, maintain close personal contact with patients and family members and can provide psychological assurance as well as medical assistance. Radiation technicians may be able to spot potential or existing difficulties and bring them to the physician's or nurse's attention. Furthermore, staff mental health professionals can be an excellent source of emotional support. For many patients, knowing that help is available allays fears, and supportive counseling efforts during the initial period are all that is needed to reduce treatment anxieties.[149]

Another source of information and counseling is other patients—either those encountered in a waiting room or in a structured group setting. Evidence of the value of informal peer counseling is conflicting, however. One study revealed that, when given the opportunity to interact with many other patients while waiting for treatment, "most . . . did not talk with anyone and the remainder interacted only with a few during their weeks in the clinic.[170] Exposure to dying patients or to those requiring second or third courses of treatment appeared to limit communication drastically. But another study found that, even without formal organization, many patients were able to share remedies for common physical complaints. Based on that observation, the study authors proposed group sessions as an adjunct to other support efforts, noting the necessity for a skilled professional group leader.[140] Examples of support groups can be found in *Appendix A*.

Contrary to logical expectations, completion of therapy can produce anxiety in some patients, as indicated in a study of women receiving radiotherapy following mastectomy or surgery for gynecological cancer.[3] Patients nearing the end of treatment felt less hopeful, more vulnerable to the disease, and feared losing frequent contact with familiar staff members. Suggestions for smoother transition include:

(1) discussing the end of treatment well in advance to allow time for emotional preparation, with reassurance of the physician's availability by telephone;

(2) scheduling a followup visit shortly after treatment to diminish the feeling of loss; and

(3) assuring the continued availability of the staff member who related best to the patient.[90]

8. CHEMOTHERAPY

The side effects arising from chemotherapy, whether it is used as primary or adjuvant treatment, have a wide range of physical and emotional consequences, depending on the drugs used and the individuals who receive them.[228] At best, the side effects are uncomfortable; and at worst, they can be life-threatening. Moreover, they have a great influence over how a cancer patient adjusts to and lives with his disease. Simply telling a patient that chemotherapy is a temporary inconvenience to be endured in the hope of prolonging his life may not be enough reassurance when the quality of that life seems unendurable. To be sure, most side effects abate at the end of chemotherapy, but that may be of little comfort to a patient who has just recovered from surgery, only to be told he must take medication that may make him feel sick again.

Possibly the greatest fear chemotherapy patients face is that of the unknown. Will the treatment work? What will be the side effects? How bad will they be? Will they get worse? Taking the time to answer or anticipate a patient's questions early will go a long way toward helping the patient understand what is expected of him and what he can expect from the chemotherapy—good and bad. Knowing that some side effects are predictable and can be remedied (or alleviated) also helps restore the patient's sense of control over his treatment. Armed with that knowledge, he is in a better position to cope with the treatment and any side effects it might produce.

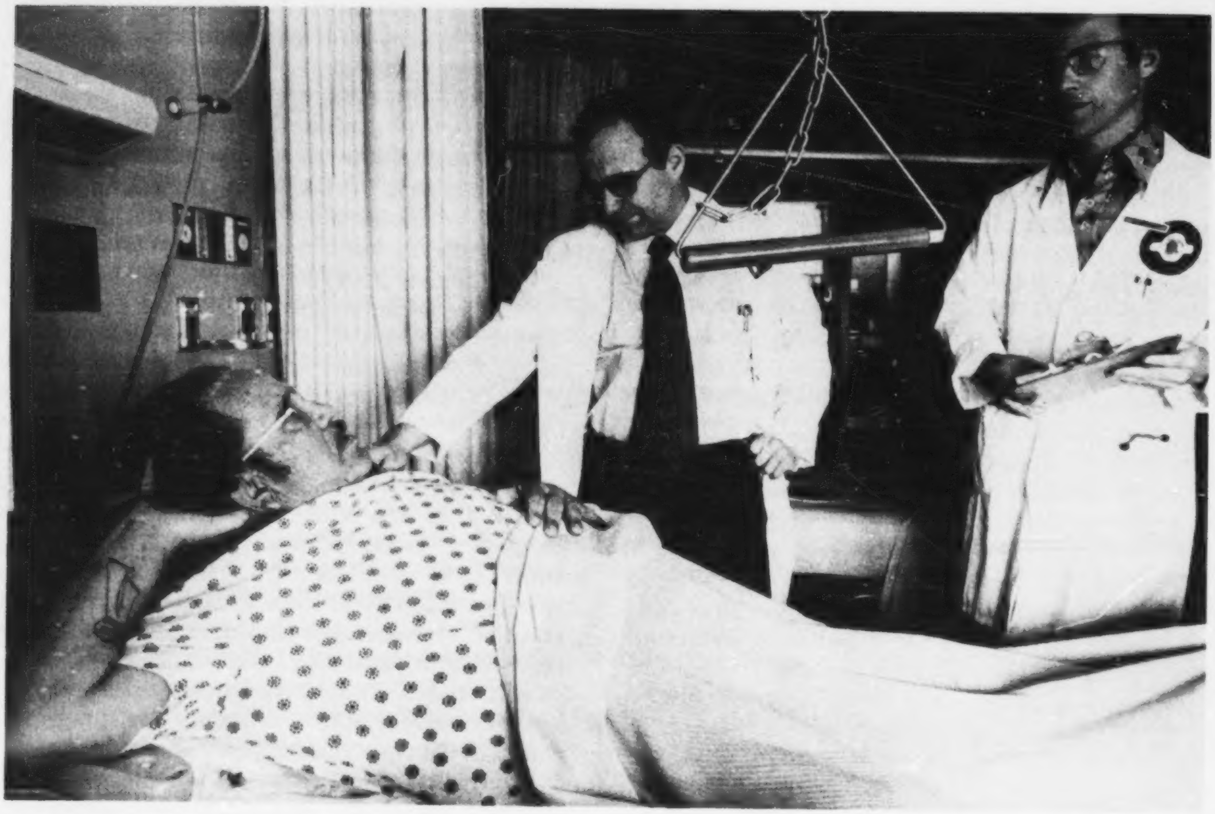
"Often the psychologic 'participation' of the patient in the drug treatment will reduce the subjective discomfort of the treatment."[12] Such participation can and should begin before treatment,[77] with a clear and thorough explanation of chemotherapy, why it is indicated (particularly in the case of adjuvant chemotherapy), what drug or drugs will be used, how often treatment will be given and for how long, and whether hospitalization will be necessary. The explanation must be handled carefully, however. The patient should be made aware of what lies ahead without being presented with an overwhelming amount of threatening information.

Patients should be reassured that caregivers will make every effort to minimize side effects, including reduction of drug dosage and adjustment of treatment schedules (where possible). Information about side effects should include measures patients can take to alleviate them, as outlined in the following discussion of commonly experienced reactions to chemotherapy.

A cause of great mental anguish for many patients is the loss of hair that accompanies certain drugs. According to one patient:

> Undoubtedly the most devastating side effect of my chemotherapy—even worse than the nausea—was losing my hair. That may sound ridiculous. But I don't think you realize how much hair is a part of your identity until you lose it. When it falls out, it's like watching your body disintegrate before your eyes. You begin to realize just what this disease can do to you.[37]

Although hair generally grows back after treatment and regrowth may begin while the drugs are being administered, even temporary hair loss can be a serious blow.[87] No matter how casual or intellectually equipped patients may seem, few are emotionally prepared for the shock of seeing clumps of hair coming out on their hairbrushes or pillows. If hair loss is anticipated, caregivers can suggest purchasing a wig or toupee early in the regimen. Such hairpieces are tax-deductible medical expenses, and may be supplied at reduced rates or without charge by some institutions.



Explanations of chemotherapy, possible side effects, and measures to alleviate them should precede treatment.

Because the patient may have no previous experience with hairpieces, recommending a shop and telling him how he might defray the expense can be quite helpful.

Nausea and vomiting can be alleviated to a certain extent by oral medication and suppositories, and can also be minimized with proper dietary support. Caregivers should emphasize the need for good nutrition, but for the patient who does not feel like eating because of side effects or anxiety about treatment, that recommendation may be difficult to carry out. Nurses caring for hospitalized chemotherapy patients might offer encouragement and assistance at mealtime. Meetings might be arranged with the hospital dietitian about foods the patient might better tolerate and find more appetizing. Outpatients and family members can benefit from booklets that discuss diet and calorie intake in general, how to make food look and taste more appealing, and what foods to prepare and to avoid for particular side effects. Some of these also contain menus, recipes, and suggestions for over-the-counter and prescription nutritional supplements.[183]

Some chemotherapy patients experience a feeling of weakness and fatigue, which may be related to the effects of certain drugs on the muscles or to other side effects, such as anemia and prolonged nausea or vomiting.[73] Combined with the unexplained nervousness and irritability many chemotherapy patients notice, these side effects can affect the ability to carry out daily activities at home or at work.[145] Caregivers can recommend dietary measures, to help alleviate the weakness and fatigue.

The stress of cancer and chemotherapy may be manifested by wide ranges in the patient's emotions. Family members should be forewarned by caregivers that "mood swings including periods of depression interspersed with spurts of heightened, almost frenzied activity" [164] are part of how the patient feels about his disease and not necessarily about those close to him.

Some issues associated with chemotherapy raise questions for which there are no sure answers. A source of anxiety for many patients is the threat of sterility. Women in their childbearing years commonly develop irregular menstrual periods; the menstrual flow may stop completely; and the ability to conceive may be impaired. On the other hand, conception is still a possibility for some and continued use of birth control measures is recommended. In men, chemotherapy often reduces fertility by lowering the sperm count and viability. Normal reproductive function in both men and women may return after chemotherapy has been discontinued, but permanent sterility sometimes occurs.[73] Sterility can present difficult emotional problems for single adults who want to marry and have children and for couples who have not yet completed their families. Caregivers can advise men about the possibility of freezing their sperm for future artificial insemination, and the possibility of adopting children can be offered to female patients. Neither prospect is entirely satisfactory to those facing sterility, and caregivers might suggest counseling for adaptation to the significant loss encountered by those patients.

A good explanation of chemotherapy, possible side effects, and measures to alleviate them requires time. The chemotherapist is probably the best person to initiate an open physician-patient relationship. If his time is limited, another staff member, such as a nurse can take his place or supplement the explanation.

Including family members in the early chemotherapy visits can reinforce explanations given to the patient, in addition to providing much-needed emotional support. In the words of one chemotherapy patient:

> I must say that having him [her husband] there has made treatment easier for me, especially in the beginning when it was all new and frightening. In fact, I think every patient would be better off if they could have a relative or someone close with them during therapy. My husband's become a real pro on my case, writing down everything the doctors have told us and discussing it with them. That's another benefit of having him there. We both know exactly where we stand—there's no deception and no confusion over whether the doctor said such-and-so or not.[37]

When discussing the side effects of chemotherapy with the patient and family, the emotional consequences should not be overlooked. Psychiatric intervention may be in order, but sometimes simply letting the patient and his family know that emotional problems are to be expected is enough to create an atmosphere of acceptance or tolerance. On the job, coworkers may be helped to understand the patient's behavior through liaison with the employer or occupational health professional, if one is available.[164]

One of the early visits is a good time to discuss the cost of chemotherapy, which can be considerable when the treatment runs over extended periods. As discussed more fully in Chapter VII, *Financial Aspects*, the patient needs to know what his insurance will cover and what support (if any) he can expect from the hospital, a research center, or social agencies. In addition, he should have some idea about what demands will be made on his employment in terms of time and money lost for hospitalization, doctor's appointments, and illness. Once arrangements concerning financial matters are made, the patient can concentrate on his treatment instead of worrying about how he is going to pay for it.

Information given by caregivers can be supplemented by booklets and other education materials that can reinforce the initial explanation and serve as references for later questions the patient and family might have.

Because of the variety of drugs used, educational materials concerning chemotherapy are difficult to standardize. If they are too general, they leave questions unanswered. If they attempt to address all anticancer drugs and side effects, they can be confusing and possibly even frightening. One solution has been developed that provides the needed personalization and flexibility. A teaching booklet giving a general explanation of chemotherapy and its most common side effects is equipped with individual cards describing specific drugs. The patient receives only the cards related to the drugs being taken.[218]

Whatever the side effects (only a few of which have been discussed here), it must be remembered that the chemotherapy patient is under unusual stress. Certain side effects—such as nausea and vomiting—are most intense during the first few days after the drugs are given (sometimes occurring within hours). As time passes, these effects usually subside and the patient begins to feel better. Yet he is always aware that another treatment day is imminent, and often approaches that day with foreboding. Other side effects—such as fatigue, weight loss, and hair loss—are delayed, occurring as the drug accumulates. As a result, the patient may never really feel well while

A task facing many chemotherapy patients is coordinating treatment and work schedules.

in treatment.

Even if the side effects are mild or completely absent, repeated visits to the doctor's office or hospital for treatment can be depressing reminders of the patient's illness. Furthermore, the sights and sounds of the waiting room can be distressing. As one patient observed: "I'm going to end up like all the others I see here—in a wheelchair or walking with a cane."[164]

Patients who have been on chemotherapy for some time may be even more apprehensive than the beginner. As the treatment wears down their mental and physical reserves, they anxiously search for verbal and nonverbal cues from the medical staff that they are improving.[164] If no improvement is apparent, they wonder about the purpose of continuing with the treatment—especially if it is causing them a great deal of discomfort. Patients receiving adjuvant chemotherapy may require special encouragement as their treatment continues, because their disease-free status from the start gives them no yardsticks for measuring progress. For patients with measurable cancer, increases in dosage (which may bring on more severe side effects) and changes to different drugs (which may cause new side effects) can arouse fears about the treatment's failure to control their disease. Patients returning to chemotherapy after several years' remission may recall their previous treatment and its side effects with dread. But overriding their concern about the treatment may be the fear that this time the chemotherapy will not work.

Letting the patient know that the physician or another staff member is available to provide medical and emotional support may comfort an anxious patient more than anything else. Something like a "chemotherapy hotline" might be established for this purpose. Special times might be set aside during the day when the physician or other staff member can be reached by phone for routine questions or just to talk. In any event, the patient should know where he can reach someone—night or day—if a situation arises that he cannot handle.

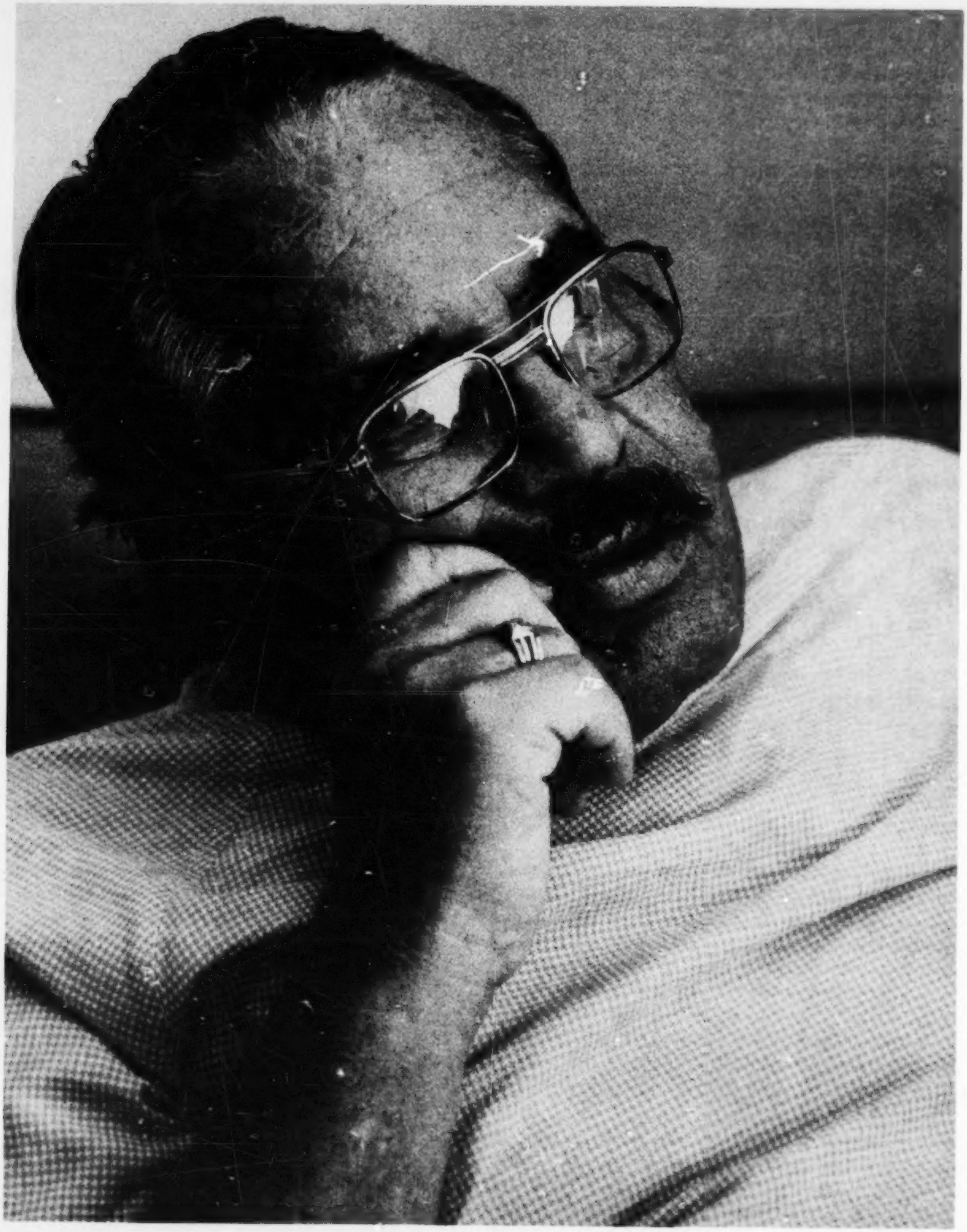
The patient who exists in the twilight world of chemotherapy, not exactly sick and not exactly well, needs help and guidance in coping with his disease and its treatment. A close collaborative relationship between the patient and the health care team is essential throughout the course of treatment. Finding the time to listen and explain, teaching the patient how he can help himself, seeking his opinion about treatment options whenever possible, attending to the small kindnesses of patient care all contribute to the patient's sense of self-worth and self-direction. What may seem commonplace or irrational to the experienced health professional is new and very real for the chemotherapy patient. After years of treatment for Hodgkin's disease, a chemotherapy veteran had this to say:

> Aside from [technical skills], the single most important attribute for a nurse or doctor working with cancer patients is just one hell of a lot of sympathy and moral support.
> You see, during chemotherapy, every patient cares only about himself. Hearing a doctor say . . . "Oh, stop it, I've heard all that before," only makes things worse. There's a fine line between feeling that it's okay to have certain fears because everyone has them and feeling that you're not important because everyone has gone through the same thing.[87]

9. REMISSION AND RECURRENCE

Completion of treatment is a milestone for the patient and family. Through surgery, radiation, chemotherapy, or some combination of treatments, the cancer has been contained or eradicated. Once accustomed to separation from the health care system, patients look forward to resuming their lives, disassociating themselves from the hospital or clinic, and abandoning the sick role. Many feel happy because they have survived the experience and are optimistic about the future. Elation, savoring the commonplace or hitherto unnoticed details of living, and general zest for life have also been noted.[87] All these feelings are tempered by anxiety, however. Although the patient may be physically asymptomatic, he must deal with the underlying fear and anxiety that the disease will recur and he will again have to undergo treatment or that the disease will become uncontrollable.[188]

Remission underscores the chronic nature of cancer. An individual may remain symptom-free for 1 year, or 5, or 10, and then develop a recurrence or metastasis. The *possibility of* disease is always present. As one patient in



Although remission is cause for elation, it is tempered with the knowledge that the disease could recur in the future.

remission stated, "It's like living on top of a powder keg, a time bomb. You don't know when it's going to go off and destroy you."[190]

A study of six patients who were in remission and being treated with maintenance chemotherapy revealed one important adjustment style: denial of the sick role.[188] To whatever degree resumption of previous lifestyle was desired or accomplished, the need to assume a well role was expressed by every patient in the study. One important proof of their recovery and return to the well role was remaining in or rejoining the work world. (See Chapter VII, Section 2, "Employability," for further discussion and suggestions for caregiver intervention.) Mental rejection of the hospital between treatments was also noted: "Once I leave here [the hospital], it never crosses my mind—no hospital, no sickness, no nothing."[188] Interestingly enough, however, family members tended to place patients in the sick role, and extended special privileges to them. This seemed to occur when little prior communication about the illness, diagnosis, and outcome had taken place, reinforcing the need for caregivers' attention to family dynamics.

As patients adjust to a life away from the hospital and caregivers, they may begin considering the long-term effects of therapy. Those who have received chemotherapy, for instance, may wonder about anticancer drugs' potential for causing second cancers. Unfortunately, there are no definite responses to such concerns. Caregivers might point out that evidence linking second cancers to chemotherapeutic agents is not clear-cut, and, to date, the benefits of treatment seem to outweigh the carcinogenic risks.[154]

Regular checkups assume great importance for patients in remission, who are understandably anxious, wondering if a recurrence or metastasis might be found. Even if patients have been disease-free for some time, the visits can be anxiety-producing. Caregivers should be aware of this feeling and continue to offer patients reassurance and support.[87]

The discovery of a recurrence may be a staggering blow; indeed, "the psychologic adjustment required may be more difficult than that of learning the diagnosis initially, because the patient knows that the curative treatment attempt has failed."[87] Once again, the patient is faced with the four issues of alienation, mutilation, mortality, and vulnerability, but this time they may be compounded by mistrust of the medical establishment. The clinical experience of one physician indicates that patients blame themselves, blame the doctor who treated them initially, or express skepticism about medicine in general.[190] Patients may feel betrayed by their own bodies and may have serious doubts about the efficacy of future treatment since the initial attempt was unsuccessful.

If the remission has been lengthy, patients and family members have probably resumed the majority of their pre-illness activities, making coping with the recurrence doubly difficult. Once again, individuals and family members must deal with the psychological issues of the illness. The possibility of dying from the disease, having been put aside for some time, may again be uppermost in the minds of patients and family members. Understandably, the perceived inability of medicine to control or eradicate the cancer through previous courses of treatment may make death a very real and frightening prospect.

Caregivers may feel equally despondent that their efforts could not prevent recurrence. The task for caregivers at this point has many facets; they must work through their own feelings, bolster the patient's confidence in the medical establishment, and communicate hope and confidence in the chosen treatment. Explanations by caregivers should include why the recurrence happened, why the indicated treatment has been chosen, and what possibilities of containment it offers.

If the initial treatment had prolonged or severe side effects, the patient is understandably reluctant to go through it a second time. Older patients particularly may be reticent to undergo further discomfort or periods of disability. Caregivers should respect these attitudes, communicate understanding of such behavior, and allow the treatment to be postponed, if possible, while the patient considers the consequences of alternatives or discusses the matter with others.[190]

At this time, families may make demands on the physician and health care institution they would not normally make. Guilt about past neglect (or what is perceived to be past neglect) of the patient may prompt family members to reject local facilities or make excessive demands of caregivers. Patients are all too aware of these stresses, and they become concerned about family members' behavior as well as their own disease.

The situation calls for a great deal of support, understanding, and patience. The physician should emphasize his desire to explore all treatment and care possibilities. He may suggest consultation with another oncologist and indicate that a multidisciplinary team is reviewing the patient's problem, demonstrating the use of all available resources. Another simple support method is letting the patient know he can call the physician or another team member: "Experience has shown . . . that just to know one has the opportunity to call . . . is reassuring." [190]

Patients and families, viewing recurrence as a failure of traditional medicine, are especially vulnerable to unproven remedies, such as special diets, plant or animal extracts (such as Laetrile), complicated but ineffectual machinery, and a host of vaccines, serums, and cell therapies.[190] Knowing this, caregivers should take special care to minimize the attractiveness of unscientific alternatives. That can be accomplished by openly discussing the possibility of unorthodox treatment, eliciting the patient's response and level of knowledge, and communicating the physician's knowledge about (or willingness to investigate) such cures.

Why patients seek unorthodox treatment at any point in the disease is a matter of conjecture among health professionals and the lay public alike. It has been suggested that people turn to unproven cancer remedies because they fear:[7]

(1) that all cancers are incurable;
(2) the expense of traditional treatment;
(3) surgery, radiation, or chemotherapy (and prefer the illusion of painless, prompt medical "miracles");
(4) that their own doctor has given up hope.

All these concerns reiterate the importance of the health care team's open, supportive relationship with the patient. Offering information, supplying an atmosphere where the patient feels free to ask questions, and expressing hope are necessary to maintain the relationship. If the use of unorthodox treatment is rooted in fear, emotional support must be provided to address that fear.

Although remission and recurrence are not heavily emphasized in the literature, psychological support and understanding are clearly vital at such times. Granted, the initial confrontation with the disease merits careful attention, but the need for caregivers' attention to patients' emotional concerns does not stop with the termination of original treatment. Coping with cancer also includes living with the threat of recurrence, and is an ongoing task for patients, families, and health professionals.

10. CONTINUING CARE

Continuing care of the cancer patient after treatment has become a process embracing all aspects of the individual's life, including physical rehabilitation in response to disability. It focuses not only on the type of cancer or organ site, but rather on the whole person and on helping him learn to live with the disease.

REHABILITATION

Authorities agree that rehabilitation should begin early—at diagnosis or at the time a workup for cancer begins—not after treatment has been completed.[46, 82, 131, 175]

Background information gathered by caregivers during the diagnostic and treatment stages of the disease is vital in planning a suitable rehabilitation program for the patient. A knowledge of previous adaptation patterns, for instance, enables team members to anticipate and minimize the impact of changes in body form and function.[147] Other factors—age, type of employment, social background, home and family circumstances—when considered in combination with the type and stage of cancer and expected disability (if any), can be used to select one of the following general approaches to rehabilitation: [46]

- *preventive*, when the disability can be predicted, and appropriate prior training can reduce the severity of its effect;
- *restorative*, if the patient can be expected only to have minimal or residual handicap;

- *supportive*, if the patient will have to tolerate ongoing disease or persistent disability, but can make appropriate gains toward control of his problems and improve his day-to-day performance; or,
- *palliative*, if there is advanced disease and basic disability that cannot be corrected.

From these general approaches, the patient, family, and health care team can formulate more specific aims: for example, a supportive approach may be chosen for a woman undergoing mastectomy, and helping her retain or regain a positive sense of femininity might be a specific aim.

The team concept of health care is ideal for meeting patient rehabilitative needs both in the hospital and at home. All team members should share planning so individual caregivers can reinforce learning goals established by the group. If, for example, the occupational therapist determines that the patient can manage self-feeding with the aid of supportive devices, the nurse will not attempt to feed him, but will assist him with the devices.

Although team dynamics are important for support, the process of rehabilitation begins with the patient. If he is to learn self-care and regain independence, he must be assisted and not controlled by those around him. Patients must be allowed and encouraged to do everything within their capabilities; the family should provide supplementary assistance, and health professionals can assist both patient and family. Implicit in this concept is the need for patients to abandon the submissive sick role as quickly as possible and to begin making their own decisions. Everything they do for themselves, even turning over in bed without assistance can help them regain their independence.

Although physical therapy for certain medical procedures including amputation, laryngectomy, mastectomy, and ostomy, requires the supervision of qualified professionals, patients can assume the responsibility for their own convalescence from other forms of surgery or from radiation therapy or chemotherapy. Some will increase physical activity on their

Home visits by caregivers can facilitate the patient's return to the community as well as provide continuing care.

own; others will need more direction, such as that contained in an exercise program developed by one hospital. With the physician's consent, the patient is given a booklet detailing a graduated series of exercises that can be started while he is bedridden and continued through discharge from the hospital to facilitate resumption of full activity.[181]

Families, too, should participate in this aspect of care. Making sure they are knowledgeable about plans, terminology, and reasons for rehabilitation is a good first step toward ensuring their cooperation and helping them to provide care beyond the institution. Educational materials covering the fundamentals of some procedures (ostomy, laryngectomy, or mastectomy) can be of assistance, as can a visit by a well-adjusted patient (see *Appendix A*, "Support Programs" and the bibliography previously mentioned). Sometimes initial information must be communicated before the patient and family can phrase questions. Those who are told preoperatively the possible outcomes of a biopsy or surgery, for example, can begin considering lifestyle changes and how to adapt to them. If caregivers wait until completion of a procedure to discuss and handle complications, the intervention may be less successful.

OTHER PATIENT NEEDS

Upon completion of treatment, many patients need assistance with interactions with others, reintegration into the community, and resumption of employment. Continuing care may mean outreach from the health care institution to assess the patient's psychological adjustment. Counseling may be necessary, as well as teaching interpersonal skills, providing a liaison between employer and patient, and locating and/or coordinating community resources to assist the patient.

One patient need that merits special attention, since it easily may have been neglected during the course of the disease, is the need for pleasure or gratification.[190] Patients preoccupied with cancer and treatment may wonder how they can be expected to consider enjoyable activities at such a time. Yet engaging in pleasurable activities can be an adaptive measure, a means to maintain self-esteem, a buffer against life's frustrations, and a reward for success [illegible] a particular activity. Encouraging patients to have fun while they are in the midst of a serious disease can be a difficult task for caregivers. One suggested approach is to expain that "the need for pleasure is as great as it is for food" [196] and that maintaining enjoyable pursuits may even alleviate emotional stress. Caregivers can also reinforce the message through consultation with family members, and encourage them all to pursue pleasurable activities.

SEXUALITY

Another basic need that bears emphasis is human sexuality, because it is "an integral part of one's values, beliefs, personality, interaction pattern, and mode of self-expression." [30] The effects of cancer and its treatment on sexuality are diverse. Some patients experience unimpaired sexual functioning, some report decreased sexual activity but increased desire for physical closeness, and some exhibit increased sexual activity. Not all patients require sexual counseling, but those who have difficulties may find that it enhances their quality of life.

To some, the process of becoming ill compromises sex role identity. The man who "equates manliness with activity and the refusal to acknowledge physical discomfort . . . may find being ill an emasculating process." [238] Cancer patients requiring hospitalization (and most do, for varying lengths of time and at various stages of the illness) may find the hospital experience a further threat to sexual identity, as well as to their dignity. Admission procedures involve the surrender of personal information, removal of valued effects, and finally, the substitution of a skimpy hospital gown for the individual's clothing. The diagnostic process, in addition to routine physical examinations, may involve intrusive procedures associated with body areas traditionally reserved for sexual intimacy. Furthermore, patients in a health care institution must adapt to lack of privacy and separation from a spouse or other sex partner.

Cancer-related psychological stress manifested as depression and anxiety may also decrease libido.[237] However, evidence from a 1976 study of patients with poor prognoses suggests that, although desire for sexual intercourse decreases after diagnosis, desire for nonsexual physical closeness increases.[122] Demonstrations of affection—holding hands, embracing, and kissing—appeared to be needed more than sexual

Affection and support from partners are vital in learning to live with cancer.

stimulation and release.

When analyzing the affectional needs of male and female patients and their spouses, the authors found that the women patients seemed to fare better than men, perhaps because they more openly expressed their desires, fears, and worries. Their husbands, on the other hand, appeared to have difficulty in fulfilling their own needs for affection. Male patients and their wives tended to differ in their affectional needs, behaviors, and major concerns, suggesting "increased intra-marital tension as a consequence of their disparate needs and altered sex roles." [122]

Specific aspects of the cancer site and treatment have a bearing on sexual performance. In addition to genitally related surgery, other operations have sexual consequences, often related to the individual's altered body image and lowered self-esteem:

> The dread of exposing oneself to one's spouse as crippled, damaged, incomplete, or dying may cause sexual inhibition or abstinence. Intimacy and sexual bodily functions may be affected by shame and embarrassment. Mutilation (e.g., mastectomy) may make exposure and nudity extremely painful. Self-disgust may be displaced and projected onto the partner. The result may be withdrawal, partial or total inhibition, decreased sexual activity, a sudden shift of interest or tastes, or a change in attitude about being touched or looked at.[76]

Other deterrents to sexual activity include general fatigue and debilitation from cancer or its treatment. Nausea and anorexia from radiotherapy or chemotherapy can, understandably, inhibit or eliminate sexual desire. Chemotherapy can also result in alopecia and body changes from steroids that affect body image.

The sexual implications of treatment are varied, complex, and difficult to generalize for the entire cancer patient population. Consequently, some questions raised by patients are difficult to answer, particularly if future reproductive capability is an issue.

Addressing the sexual problems of cancer patients and their partners is a sensitive and complicated task, limited by patients' desires to discuss sexuality and by caregivers' own attitudes and training. Assistance can be offered on many levels. Giving emotional support is the most basic means of helping patients cope with threats to their sexuality and can be as simple as encouraging self-care efforts so that patients feel attractive. Providing physical privacy for those in the hospital is admittedly a challenge to caregivers, but "allowing patients predictable times during which they can enjoy solitude or be alone with their partner is not impossible. Drawing curtains, closing doors, and respecting sexuality and sexual behavior as a natural aspect of living are all simple acts but meaningful contributions to physical and psychological privacy." [238]

Often the most helpful intervention with patients is nonjudgmental listening, requiring caregivers to have previously identified and examined their own ideas and attitudes toward sexuality. Beyond this, caregivers may be able to use the "P-LI-SS-IT" model of intervention, composed of four levels by which to approach sexual concerns.[9] In the first level, "*P*ermission," clinicians can reassure patients that their problems or behaviors are shared by others in the same situation.[9] A patient wondering if reduced sexual desire is "normal," for example, may be reassured when caregivers point out that fatigue or worry about the disease are understandable libido inhibitors. In "*L*imited *I*nformation," the second level, caregivers can provide the patient with factual information relevant to a particular sexual concern.[9] The result may be that the patient continues his behavior or that he does something different. "*S*pecific *S*uggestions," the third level, are "direct attempts to help the client change his behavior in order to reach his stated goals," and require some therapy and counseling skills from the caregiver.[9] Obtaining a brief sexual history or sexual problem history, for instance, necessitates familiarity with interviewing techniques.[29] After the interview, specific suggestions might also include giving patients information about the general effects of treatment or specific potential changes in sexual desire or functioning. If the patient's concerns are beyond caregivers' experience and confidence, referral to "*I*ntensive *T*herapy," level four, is indicated.[9]

Although caregivers need not be sex experts to be helpful, education in human sexuality during health and illness is beneficial. Curriculum or continuing education courses offer opportunities for caregivers to explore their own attitudes toward sexuality and to acquire knowledge and skills.

THE PATIENT AT HOME

Continuing care requires attention to the patient's and family's well-being beyond the hospital or clinic. After discharge, complying with the care plan, locating materials and services, and allowing for respites from the responsibilities of care may be difficult without health professional support. In some instances, contact can be maintained by the nurse or social worker who was the primary patient contact throughout the care period: "With increasingly shorter hospital stays today, a liaison person to serve as a bridge between segments of care and the patient in the community becomes increasingly important." [131]

Visiting nurses are available in some areas, and can visit the family weekly (or more often) to assist with practical care in the home. Reinforcing instructions given to patients by hospital and clinical staff members is another important duty; patients often are better able to retain information repeated in familiar surroundings. Visiting nurses can be especially helpful to those who live alone and require guidance in their own care.[19]

A demonstration project funded by the National Cancer Institute is exploring another method of postdischarge care, rehabilitation carried to the patients' homes.[14] The team consists of three medical social workers (functioning as team coordinators), two public health nurses, a physical therapist, an occupational therapist, a child life worker, a vocational-educational counselor, a health educator, and consultants reporting to the project director. The program's goal is to provide total family rehabilitation and to coordinate existing community resources with at-home services; patients and families are referred by physicians at area hospitals.

Overall rehabilitation plans originate in the hospitals, and the home rehabilitation plan is prepared in cooperation with the referring physician. The team communicates frequently with the referring physician regarding patient and family progress, and revised plans are sent to the physician for approval and modification. A wide range of services is available from the project team; implementation in the home is a tremendous advantage. The physical therapist, for instance, can evaluate architectural barriers encountered by the patient at home, school, or work. Nutrition can be reviewed in the family kitchen and educational films can be shown in the living room. Supportive counseling is offered to all members of the family. Children receive special attention from the child life worker, who can involve them in activities while the social worker consults with the parents. Since the team makes frequent visits to the home, members can spot patient and family problems for referral to other professionals, and can recommend community resources where appropriate.

Whatever the approach, the focus and philosophy of continuing care and rehabilitation remain the same:

> To change "dependent" to "independent" we add only two letters, but helping a person become as independent as possible by coping with loss due to cancer adds immeasurably to the quality of life. It takes the cooperative efforts of everyone to reach this goal: the hospital team, home care professionals, and the patient and family members.[143]

IV. Cancer in the Young

1. ISSUES

The outlook for the survival of children with cancer has improved dramatically in recent years. Childhood cancer was once considered a swift and certain killer. Today, treatment techniques capable of producing disease-free states (remissions) have increased length of survival and, in some cases, have brought about apparent cures. (Many treatment techniques are too new to supply data for 10 or even 5 years of use, common benchmarks for cautious pronouncements of cure.)

Taken together, the latest statistics from groups specializing in the treatment of childhood cancer show the scales tipping toward survival for the child with cancer. According to one pediatric oncologist, "Our current state of knowledge and skills is such that in the best cancer treatment centers it is possible to eradicate the disease in at least 50 percent of all children with cancer who come for initial treatment of their disease." [235] This is not an uncommon statement. Others in the field also point to the advances in survival produced by new treatment techniques.[138, 172]

The increased chance for survival of the child with cancer has created new issues in pediatric oncology and has changed the needs of caregivers, patients, and families, and their relationships with one another. The issues to be discussed throughout this section on childhood cancer generally revolve around the changing status of these children. Once coping with childhood cancer involved the acceptance of a poor prognosis and the feelings that accompanied seeing a child rapidly deteriorate and die. Today, childhood cancer in general can be viewed as a chronic illness with an uncertain outcome—the child may be cured or may die. Treatment may extend over years. Remissions are common, but so are recurrences. Although the child has a life-threatening illness, he is still growing and developing, and has needs similar to his healthy age-mates. The physical and psychological demands on the patient and family are great and disruptive on many levels. The child, family, caregivers, and community must cope with a host of factors.

Although more children are surviving longer, treatment efforts are not always successful. Some childhood cancers are clearly more responsive than others to new treatment techniques, but children are still dying of cancer. Survival rates and hopeful predictions for cure are couched in terms of percentages, and even for those cancers with the highest chance of survival, no one can tell for certain which child will live and which will die. So, for children with cancer and their families, the problems of a chronic illness are compounded by uncertainty and the threat of death. This threat and the fear that accompanies it are part of living with childhood cancer and will be considered here in that context.

Much of the literature on the emotional effects of childhood cancer focuses on the family, particularly the family of the dying child. Other articles focus on caregiver attitudes and the ways in which individual caregivers and treatment teams can help the family and child cope with cancer and all that goes with it. Information on the child's reaction has been primarily anecdotal and few studies have centered on this area. This emphasis on families and caregivers is probably due to the fact that, for years, children with cancer seldom remained healthy or alive long enough for their feelings about their illness to be analyzed. Secondary reasons may be less objective, as one group of researchers speculates: "In retrospect it seems almost as if we first had to come to grips with our own feelings and attitudes about a child dying before we were able to look at the child's own reaction to his impending death." [72]

Although more information on the child's reaction is needed, understanding the reactions

The diagnosis of cancer in a child arouses many emotions in adults—anger, fear, powerlessness, and a strong desire to protect the child.

of those surrounding him is a necessary undertaking. These people are, after all, central to the child's existence. He depends on them for care and for a sense of himself. Their reactions to him influence his reactions to himself. Studies and observations of families point repeatedly to feelings of guilt, frustration, anger, futility, and despair. The community often isolates the child and family, out of ignorance and fear perhaps, but also out of feelings of inadequacy. Most people are uncomfortable with illness and pain when they encounter it in an adult, even one who has enjoyed a long life. To face this in a child is particularly difficult. We want to protect him from pain and suffering, but we are powerless to do so; we want to explain why this has happened, but we have no explanation; we want him to live as other children, but we must learn, as he must, to accept the reality of cancer and to live with it.

What follows is an attempt to describe the issues involved in coping with childhood cancer and how to address them. However, as one parent of a leukemic child points out,

> . . . on the human side the questions *are* without answers. Protocols can be arranged with different therapies to determine the correct way to treat the illness but people's reactions are not easily quantifiable. We can identify questions and propose solutions, but there will never be one answer to the complexity of human emotions.[192]

2. DIAGNOSIS

The diagnosis of cancer in a child has repercussions for everyone in the family. Each family member will be affected by the disease and in turn will affect the adjustment of others.[169] Parents and siblings must develop methods of coping with their feelings and fears about the child's cancer. They must also adjust to the practical limitations placed on their lives by the child's illness, as well as the feelings these limitations arouse. From the moment of diagnosis, their lives are changed. Nevertheless, the family must go on. Despite their own feelings, parents must continue to function and to provide the child with the support he needs. One mother described her first experience as the parent of a child with cancer in this way:

> Of the subsequent hour I remember little—time perhaps, has mercifully obscured it; other overwhelming years have intervened. I sat in one chair in the doctor's office, he in another one. With my hands in his, he told me that Elizabeth had acute lymphocytic leukemia; treatment would be started the next day, when the necessary drugs were to be brought in from Cleveland. She would live, he said, for 2½ or 3 years. Later, with a friend accompanying me, I returned to the hospital to be with Elizabeth. Large double doors led from the entrance hallway into the corridor where her room was located. Three times I pushed through those doors and started down the hall, only to turn back as I became engulfed by sobs. The fourth time I made it to her room and I walked in with a smile. "Hi!" I said. "I guess I took a while, didn't I?" Such was the beginning.[201]

Increased recognition and understanding of families' reactions to childhood cancer have led to efforts to help them cope. More and more treatment center programs now consider the stress on the family, as well as the child, and attempt to deal with it. The treatment team that does this may be organized in a number of ways, depending on administrative philosophy, and hospital and community resources (see Section 4, "Treatment and the Health Care Team" of Chapter III, *Cancer in the Adult*). Potential members of the treatment team include physicians (representing all specialties involved in the child's case, including psychiatrists), psychologists, nurses, social workers, play therapists, child life workers, rehabilitation specialists, chaplains, parents whose children have had cancer, teachers, and in some cases, the patient and family themselves. Support groups for families and patients exist both within treatment centers and through outside organizations (see *Appendix A*, "Support Programs").

At the time of diagnosis, the treatment team can begin studying the family to assess potential coping skills. This may be done through interviews and observation, most often by social workers or nurses. They may look at several factors, including ability to cope with previous stress situations, finances, lifestyle (for example, one- or two-parent home, whether both parents work), and whether the child is hospitalized away from home.[38]

Assessment of the marital and parent-patient relationship is necessary, as is determining if an extended family exists that might be able to provide additional support.[47] Special inquiries about the ages and personalities of siblings should be made, as well as some determination of their relationship to the patient.[60] At some treatment centers, families are referred to the team psychiatrist or social worker for counseling if serious problems are expected. At others, the counseling staff attempts to provide ongoing support to families of all patients.

Through learning about the family and patient, caregivers are able to establish not only what coping skills and support are available, but also how to enhance those skills and support. The information collected is basic to the necessary task of preparing the family for what lies ahead.

In terms of helping patients and their families cope with childhood cancer, it must be remembered that, for the most part, these are normal people going through an extremely difficult time:

> Basically sound families are confronting an inordinate amount of stress, which they are powerless to control. In such circumstances even the most well-adjusted families will be unable to escape reactive emotional difficulties linked to powerful reality events.[107]

For mental health professionals, this places a low priority on traditional tasks such as uncovering and interpreting the unconscious. Instead, emphasis should be placed on practical, supportive measures "including facilitating communication among family members, encouraging the expression of significant emotional concerns, assisting in the management of reactive behavior problems, and sensitizing clients to the emotional subtleties which are easily overlooked." [107]

Times of heaviest emotional stress and corresponding need for support reflect the course of the child's illness—with diagnosis, major treatment episodes (such as surgery), hospitalization, onset of side effects, relapse, serious infection, and death being the most difficult. Patients and families may need intensive professional help at these times. This additional support, offered by treatment teams throughout the country, is clearly vital to the patient's and family's ability to cope with their situation.

Some families have emotional problems before the diagnosis and these can only be exacerbated by the pressure that follows. In others, maladaptive responses to the diagnosis and disease can produce psychopathological conditions such as symbiotic relationships between mothers and patients [118] and classic school phobia [119] in families with essentially normal histories. Recognizing both types of problems and attempting to alleviate or, in the case of maladaptive responses, prevent them are important elements in helping the patient and family adjust to cancer.

THE PARENTS

In childhood cancer, it is the parents, not the child, who first hear the diagnosis and are most acutely aware of its implications. Even if they suspect what the diagnosis will be, few are prepared to hear their worst fears confirmed. Faced with a situation over which they have little control, parents naturally have strong reactions. They may react to the diagnosis in a number of ways, including disbelief (being "stunned"), anger, guilt, and grief.

A study of 16 families whose children had died of leukemia reported that, for many parents, the diagnosis was the hardest blow they had to bear throughout their child's illness. In the first days and weeks that followed, they had feelings of physical distress, depression and inability to function, anger, hostility, and self-blame.[27] Although not pointed out by this study, denial may also be a response to diagnosis.[201, 28]

Another study of parents whose children had been successfully treated shows that the period of diagnosis evokes painful but vivid memories 5 to 10 years later.[65] Looking back, these parents reported that, "Although they continued to function adequately on behalf of their child, they had still felt an underlying sense of panic, helplessness, confusion, and fear that their child might die." [65]

All of the reactions mentioned above are not only common, they are natural. Unless they become overpowering and interfere with functioning, they may be coping mechanisms themselves.

In the initial meeting with the parents, the physician and, in many cases, other members of the treatment team, explain the diagnosis, intended treatment (which may begin almost immediately), and prognosis. Treatment alternatives and their advantages and disadvantages may be reviewed. Both parents, if available, should be present at this initial meeting, since it is difficult for a parent who is upset to absorb the information and pass it along correctly to the spouse.[47] Most sources agree that the parents should be given a realistic picture of their child's chances for survival. However, in the rapidly changing world of childhood cancer treatment, this need not exclude hope, even for those cancers with the lowest success rates.

Extending hope in a realistic way was found to be important in the previously mentioned study of parents whose children had been successfully treated. The parents who recalled the diagnosis with strong feelings of anger were those initially given little hope. Negative memories were most often related not to poor medical care, but instead to the physician's attitudes. Parents who were satisfied with their child's treatment recalled their physician offering hope.[65]

From the time of diagnosis, parents face many decisions. It is not uncommon for them to disagree on important issues; they may react differently to the diagnosis or disagree about the implications of the disease. Such disagreements impede communication and weaken support systems vital for effective coping. Successful coping with diagnosis is essential, as it may set a pattern for successful coping with future tasks.[208] By being aware of the potential for conflict and its implications, caregivers can assist parents in resolving major disagreements and communicating with each other.

In many programs, rehabilitation begins the day the diagnosis is made.[38, 235] Indeed, this is the time for caregivers to establish a relationship with the parents and to begin assisting them in the tasks that lie ahead. In meeting with parents, "aggressive attempts should be made to begin on a basis of honest communication, encouragement of questioning, and respect for the psychological defenses, including denial, that may be employed by parents." [126]

The family may retain little information from that first meeting. Knowing this, treatment team members can expect questions from family members, who may have unwarranted fears or fantasies.[84] A meeting between team members and the parents a few days after diagnosis may reinforce information relayed in the initial meeting and allow assessment of the parents' understanding of the disease, its side effects, and treatment.[47] Caregivers may wish to supply written materials on the child's illness and/or treatment, or direct parents to other sources of these materials. Eventually,

> the patient and his family should have an understanding of the disease, the therapy planned, and the things that they and other treatment team members must do in order to offer the best possibility for the successful resolution of their problems.[235]

The diagnosis of cancer raises many questions for the parents. One of these is how and what to tell the patient and siblings.

THE PATIENT

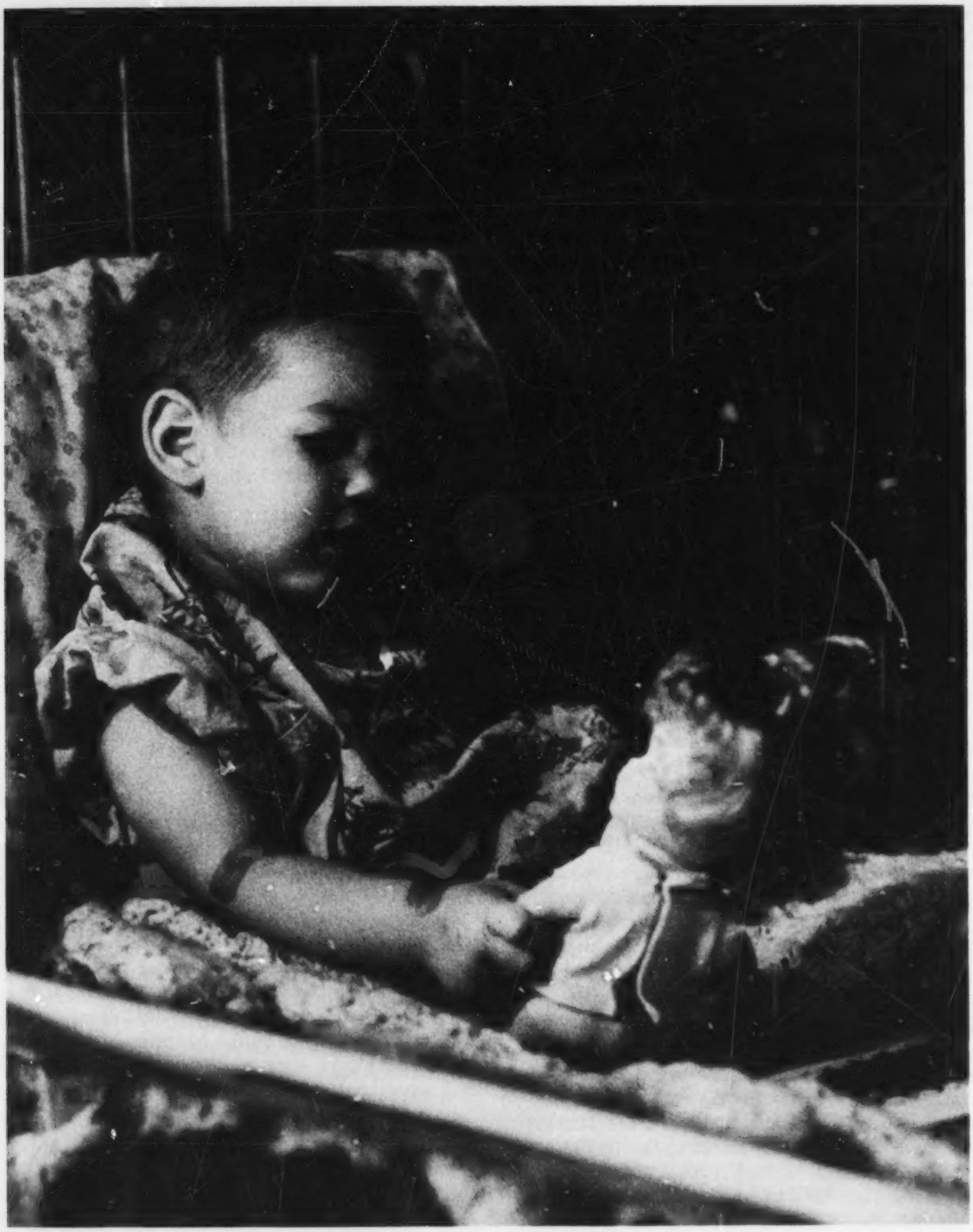
There is general agreement that the patient should be told as much about the illness as his age allows him to understand. As one handbook prepared for parents whose children have cancer points out:

> It is virtually impossible to isolate the child from the fact that he is seriously ill. He is certainly different from his playmates for he has to go to the doctor frequently, and may be hospitalized on numerous occasions. He takes special medicines and his parents are likely to show extra concern about his health. Indeed, from the very time the diagnosis of leukemia or a solid tumor was first made, his parents and his physician have probably acted in a far more serious manner than ever before.[34]

One cannot assume that, simply because a child does not talk about his illness and the fears relating to it (including death), he does not have these fears. A study of fatally ill children with leukemia, ages 6 to 10 and previously assumed to be too young to have an awareness of death, found these children's anxiety levels to be higher than a control group of chronically ill children who did not have cancer.[207] These children appeared to be aware of the seriousness of the illness, even though they may not have been intellectually capable of discussing it in adult terms.

Older children have even more clues. They may have read or heard about cancer and may guess their diagnosis. An older child may talk with other children in the hospital who have been told about their condition, and he may realize that their symptoms and treatment are similar to his own.

The child who knows that his illness is more serious than the usual childhood disease is undoubtedly afraid, and secrecy tends to isolate him and increase his fears. Children can be helped most when caregivers and parents are open and create an atmosphere where the child may express his concerns and feelings. Caregivers



Although young children with cancer may not be able to verbalize their concerns, they know that their illness is serious and that they are somehow different from other children.

should stress to parents the importance of maintaining honest communications with the child:

> Failure to answer a child's question in an honest fashion when he already knows the truth undermines the basic parent-child relationship at a time when the child needs desperately to communicate with his parents.[34]

Older children who know about their condition but realize their parents do not wish them to know may attempt to protect their parents by feigning ignorance. One group of researchers calls these children "the loneliest of all," as they have no one with whom to openly express their feelings of sadness, fear, and anxiety.[27]

For younger children who may not yet be able to verbalize their feelings, these concerns still exist. Caregivers may need to point out to parents that reassurances and explanations appropriate to the child's age are still necessary. Treatment team members' knowledge of child development and previous experience with other children can supplement the parents' knowledge of their own child in finding a way to explain the diagnosis and treatment that is appropriate to his level of understanding.

Most children with cancer will eventually be released from the hospital and return to their homes and previous activities while treatment continues. This places them outside a controlled environment and in situations where others may supply a name and prognosis for their condition. Excluding them from outside activities may keep them from learning their diagnosis, but it also threatens their development. It reinforces their fear of being different and contributes to a sense of alienation. School-age children with cancer should, for example, return to school as soon as possible, and problems for the teacher, parents, schoolmates, and child are compounded when the child has not been dealt with honestly.

Whether in or out of the hospital, the child must trust the treatment team and participate fully in his own treatment. Modern treatment techniques require much of the patient, and to give his all, the child must form a therapeutic alliance with his parents and the treatment team. Such an alliance requires absolute trust, where the child knows he will be kept informed; it requires sharing knowledge to the limits of the patient's ability to understand it.[126]

The information provided to parents, patients, and siblings may in fact help them cope with the disease. Cancer in children is often accompanied by feelings of loss of control. Information on the disease and treatment protocols may be used by patients and their families as emotional supports to help them cope with the illness and subsequent sense of helplessness.[126]

THE SIBLINGS

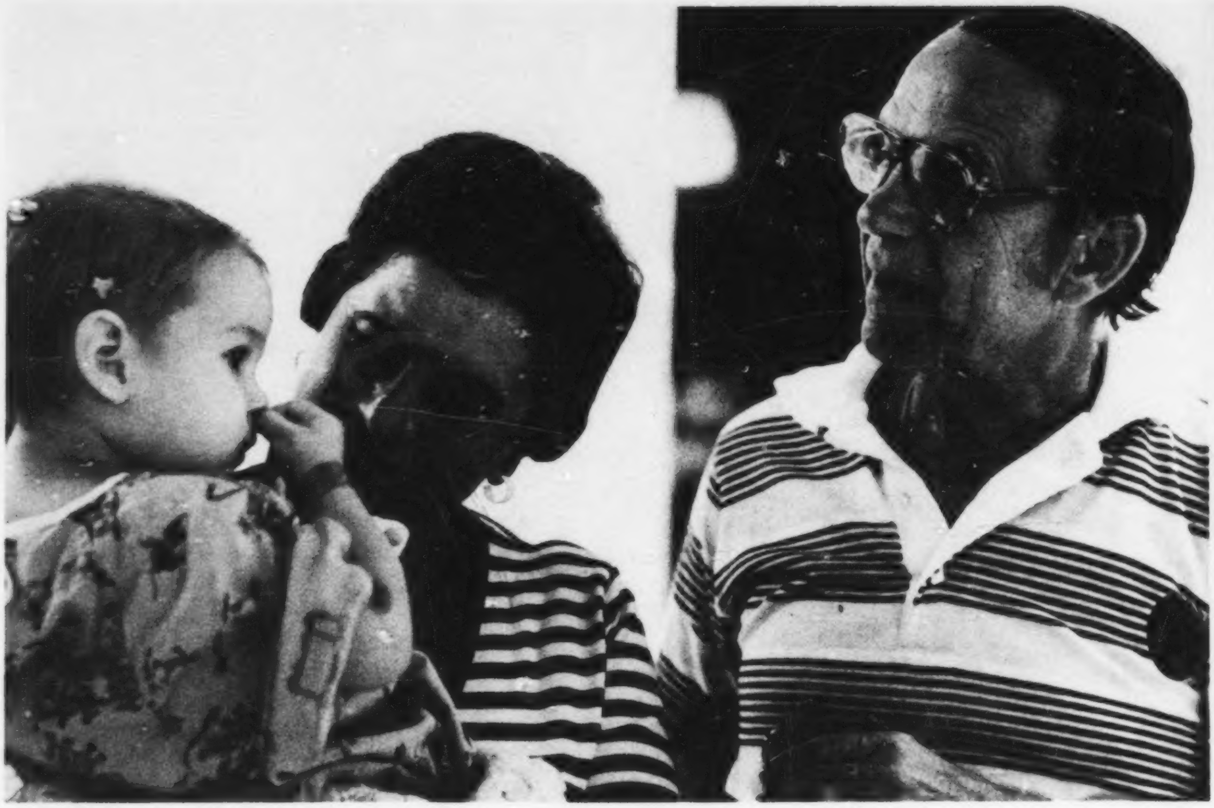
The other children in the family should also be told as much about the child's illness as they are able to comprehend. At the most basic level, children need to understand that cancer is a complicated disease and unlike illnesses they may have had themselves.[34] To ease common fears, siblings should be made aware that: (1) the illness is not contagious and they need not worry about catching it,[34] and (2) the cause of the disease is unknown and nothing anyone did caused it.[47] This information may be conveyed by parents or caregivers.

Whenever possible, treatment centers should encourage siblings to come to the hospital soon after diagnosis, before they have constructed strong fantasies about the hospital and the hospital experience. Fantasies may range from fearing that the patient is being tortured to believing that he is having a good time; siblings may be terrified or jealous.

The period of diagnosis is difficult for siblings. Their parents are upset and spending time at the hospital; their brother or sister is very sick, and they may feel frightened or guilty. A sibling's reaction to this stress may not be as supportive as the parents expect. Caregivers may help parents and siblings by encouraging the parents to spend time with the siblings as well as the sick child. Most important, parents should be helped to see beyond their own guilt, grief, and fear and to recognize the same feelings in their healthy children.

GRANDPARENTS, OTHER RELATIVES, AND FAMILY FRIENDS

When a child is diagnosed with cancer, it affects not only his parents and siblings, but also his grandparents and other relatives and family friends. Ideally, these people can provide support and assistance. They can babysit and spend time with the siblings, stay with the sick child to relieve the emotionally exhausted parents, or assist in the many practical problems that arise



Grandparents can help with care of the sick child, allowing parents a respite for time to themselves.

when a household must continue to function under stress.

Unfortunately, they are not always able to do this. Grandparents may feel particularly lost and helpless, since they are concerned about the grandchild and at the same time cannot stop the suffering of their own child. If grandparents do not understand and accept the situation, the parents of the sick child may find themselves in the difficult position of dealing with their own grief while attempting to support their parents. Treatment team members can ease these difficulties by, for instance, offering to explain the child's condition to the grandparents. Being allowed to participate in meetings of parents' groups may also help grandparents deal with their feelings about the child's illness.[117]

General assistance to parents in dealing with other family members and friends may consist of discussing potential problem situations and assuring parents that they can turn to caregivers for advice. Parents may find that relatives, particularly those who are physically removed from the family, question the reality of the diagnosis or the advisability of the chosen treatment. Such well-intentioned suggestions may tax parents' own attempts at coping. Caregivers can offer parents examples of how others have dealt with such situations, as with one mother of a child with leukemia:

> We usually found we were the ones playing the supportive roles in our families, at first reassuring: "Erin will probably live for 2 years. We should all try to treat her normally," and so forth. Responding to the initial comments and questions was often unnerving. "No, extra vitamins and orange juice will not cure her." "Yes, we did read about that report of a cure in Mexico, but we're sure if it has any validity our doctor will know." "No, I don't know of anything I did during pregnancy to cause this." "Yes, we feel our treatment center is doing everything it can." [179]

Treatment center staff can also help by pointing out that friends may feel awkward and uncertain about how to help. Caregivers can emphasize that family members often must take the lead in dealing with friends. Describing an experience in a local market, this same mother noticed people avoiding eye contact:

> We soon realized the communication was up to us. We would respond to a mumbled, "Hi, how are you," by saying, "You know Erin has been quite ill but she is coming along pretty well now." The obvious and visible relief was worth the effort. They really did care but just didn't know what to say.[179]

Knowing in advance that family members may have to show others how they wish to be treated can help family members then find sources of support early in the illness. Establishing communication with those a family has relied on in the past will ease the return to normal life, essential for the family and the child's development and involvement in the community.

3. TREATMENT

The child and his family may have little or no time to absorb the diagnosis before they are plunged headlong into the bewildering world of treatment. Thus, they must begin coping immediately not only with the diagnosis, but also with the treatment, which is often aggressive:

> Not infrequently, coming to grips with the diagnosis is partially undone by the inability to do the same with the treatments, the former being completely out of the child's (and family's) control, and the latter done only upon their agreement and with their "informed consent." [107]

Experience with cancer will vary depending upon the type of cancer the child has, and the child's reactions will, of course, depend on his age. Although some of the literature on treatment, remission, and recurrence is general, much of it centers on the preschool and school-age child with leukemia. That emphasis will, of necessity, be reflected here. Even when the specific reference is to leukemia, many of the feelings and experiences of patients and their families can be generalized to include other childhood cancers.

The effects of treatment may be put in perspective by a closer look at the therapy process for acute lymphocytic leukemia. In treating this type of leukemia, the child is hospitalized immediately and given treatment to induce a remission. The time required for this varies, but he may be hospitalized for 1 to 4 weeks. After remission has been achieved, the child is released from the hospital and treated in the outpatient department for a few more weeks to consolidate the remission. During this time, specific therapy designed to prevent development of central nervous system leukemia is undertaken.

Once that process has been completed, the child must return to the clinic every 3 to 6 weeks for treatment aimed at maintaining the remission. These treatments may vary in length, with the child spending most of the time in the clinic. Maintenance therapy usually continues for 2½ to 3 years. If there is a relapse, the process starts again, and intensive treatment is reinstituted in an effort to bring about another remission. During all this treatment, the child undergoes fingersticks, lumbar punctures, infusion of chemotherapy drugs into the blood and cerebrospinal fluid, x-rays, and bone marrow punctures. Each of the chemotherapeutic agents may cause a number of side effects, such as nausea, vomiting, and hair loss. In addition, the drugs may cause temporary lowering of the white blood cell counts and put the child at a greater risk of infection.

Consider what the process demands of the child and his family: acceptance of treatment without assurance that it will eradicate the disease, pain and fear, hospitalization, frequent clinic visits, possible financial problems, and disruption of family life. If the family lives in a city other than the one where the child receives treatment, disruption and logistical problems are increased. Treatment is a lengthy process. For a period of years, the family's life will revolve around the child's cancer. Speaking of leukemia treatment and its effects, one author says: "Modern treatment initially demands complete disruption of the patient's and the family's life. Partial disruption never ceases while the child lives." [84] As a result, cancer leaves its mark on every member of the family, sometimes to the point of threatening the stability of the marriage and the security of the siblings.

Cancer in a child may tend to lock parents into the traditional roles of mother as caregiver and father as wage earner.[192] Even if she is employed, the mother is frequently the family member most involved with the child's illness.

Fathers should be encouraged to spend time with the sick child in the hospital, both to involve them in the child's care and to relieve the mother.

She becomes quite familiar with the details of treatment and is usually the one to stay in the hospital with the child and make trips to and from the clinic. Fathers are generally not as involved:

> Fathers, for a mixture of reasons ranging from economic to cultural role expectations, are infrequently present and thus develop a different sense of the disease and treatment process, a sense which provides an experiential distance between them and their wives.[84]

Mothers may resent the father's ability to escape the tense home and hospital situation, and fathers may resent the mother's ability to spend time with the child. Fathers may also feel that the doctor-mother-child relationships threaten their position as the family's key decision maker.[102]

Their different roles may make it more difficult for parents to help one another in a crisis: "Because of the differences in their interactions with the life of the child, a fatal outcome may find parents far apart in their reactions and stages of grief, and unable to comfort each other."[102] Mothers' experiences in the clinic and hospital are generally felt to give them an advantage in coming to terms with their grieving.

Increased efforts are being made to involve fathers in the care of the sick child and to bring the parents' level of involvement closer together. Fathers should be encouraged to stay in the hospital with the child when their work schedule allows, such as on weekends, and to take the child to the clinic.[102]

Such efforts are important, as distance between the parents can be deleterious to their relationship. For example, a situation can develop where parents use their limited time together to talk only about the child's condition. Their prediagnosis pattern of communication may be abandoned, as they no longer take the time to talk about themselves, their relationship, their plans, or even about the other children. As a result, both parents may feel neglected and misunderstood.[113] Caregivers have become increasingly aware of such problems and may attempt to alleviate them by counseling parents and encouraging them to take time for themselves.

Studies attempting to pinpoint the degree of strain that can be created in a marriage by a child's cancer and the results of this strain have differing conclusions.

One study of 40 families whose children had died of leukemia found that, 3 months after the death, 5 percent of the parents had divorced, 18 percent were separated, and 70 percent reported serious marital problems. Where marital problems existed, they were most frequently reported to have worsened after diagnosis. Later contact showed an increased number of divorces.[97]

Another study of families whose children had been treated at a cancer center some time during a 7-year period found a smaller incidence of divorce: eight among the 188 families responding. This divorce rate of 1.19 percent was lower than the average rate of 2.03 percent for the two states covered by the center.[115]

Although researchers did find marital problems in still another study of 38 existing marriages, they found no evidence to support the theory that cancer in a child increases the likelihood of divorce.[115]

Siblings of the child with cancer must adjust to a situation in which much of their parents' attention is focused on their sick brother or sister.[105] They are aware of and respond to stresses experienced by their parents, but they have stresses of their own. They may be anxious about the child's illness and fate and also concerned about their own health. They may feel guilty that they are well while he is sick. They may resent the special attention he receives. This resentment may result in hostility being focused on the patient, who appears to be getting all the attention and around whose condition the family's life is planned. Such behavior may be seen as a sign that siblings' needs are not being met. Without intervention, this can lead to serious behavior problems.

One study of families of children who had died of cancer showed that, in approximately half the families, previously well siblings exhibited behavior patterns indicating difficulty in coping.[27] These included headaches, poor school performance, school phobia, depression, and separation anxieties. The study found that siblings complained their parents were preoccupied with the sick child, and the siblings felt rejected as a result. They also felt guilty and feared they too might suffer a fatal illness.

Another study using psychological testing methods shows siblings' concerns to be similar to the sick child's. Both groups had high levels of anxiety and saw themselves as being vulnerable to catastrophic injury or illness. Interestingly, it was the siblings and not the patients who showed the greater concern about isolation from others and dependency. Although they thought the sick child was overprotected and overindulged, the siblings were reluctant to express negative feelings about other family members, perhaps out of fear of jeopardizing their precarious position in the family.[113]

Taken as a whole, the literature recommends counseling to help siblings express their feelings, involving them in the sick child's care by allowing them into the hospital or clinic play areas, and keeping them informed. Being honest with these children about the sick child's condition and allowing them to become as involved as possible can help them adjust to the sickness and the situations that arise from it.

HOSPITALIZATION

Hospitalization is a difficult time for both the patient and his family. The initial hospitalization thrusts them into a new and confusing environment, where the patient undergoes painful or frightening treatments while parents must watch helplessly and face their loss of control—they cannot protect the child from the illness nor bear the pain of the treatment. Moreover, the necessity of hospitalization forces them to admit that the illness is serious. Subsequent hospitalizations, particularly those caused by recurrence, are also difficult times because of the fears aroused when treatment fails to control the disease.

A study published in 1955 on the psychological impact of cancer on mothers of children hospitalized for leukemia showed that hospital routines brought about changes in the mother-child relationship that the mothers found upsetting.[28] Nurses or other staff members were responsible for many functions ordinarily performed by the mother, including feeding, clothing, and disciplining the child. Some mothers displayed a sense of rivalry with the nurses over the child.

Since that study, changes in hospital procedures have eased many of the complaints. Where parents were once confined to limited visiting periods and excluded from the child's care, they are now often given unrestricted access to their child and urged to participate in care. It is common for one parent to stay in the child's room. A parents' sitting room, bathroom, and bedrooms adjacent to the pediatric oncology ward for use by parents when the child is hospitalized for extended periods may also be provided.[59]

Family members may be encouraged "to stay in the hospital with the child whenever possible, help with their care to whatever extent they can and elect to do, and to learn as much about the child's disease and treatment as they desire."[235] Meals can be served family style and family members can help prepare special foods in a designated cooking area. Parents can observe and assist in the child's treatment, and may work with nurses and physicians in caring for the child, even at the most critical periods. In some cases, they may have free access to the patient's medical records.

In such a cooperative effort, team members (including the patient and family) work together and provide each other with needed information. Medical and nursing staff educate the patient and family about the illness and its treatment; the patient and family educate the medical and nursing staff about the patient and how the therapy and its effects can best be managed to have a minimal effect on the family's lifestyle.[234]

As for the children, they

> should be encouraged to be out of bed and dressed in their regular clothes. The need for an intravenous needle in the arm should not automatically mean that the patient must be confined to the hospital or cannot carry on normal activities.[234]

Allowing patients to go to movies with an IV in their arm and a nurse or parent along to see that everything's all right is not common, but it can be done.

Children's reactions to hospitalization vary according to their ages, but even infants can respond to painful treatments. One author says that children as young as 4 months can develop phobic reactions to white coats and treatment personnel because they have learned to identify them with pain.[51]

The responses of older children can be more clearly defined in terms of general emotional reactions. Anxiety in young children may center on fear of separation from the mother, while older children may fear bodily injury, mutilation, and loss of control. (The special concerns of adolescents are outlined in a later section.) Regardless of age, children who are hospitalized fear separation and react with

Parents often feel a loss of control as their child receives care from others, and powerless in their inability to protect the child from the illness and treatment.

anxiety and sometimes hostility.

In the hospital, the child may show this anger, anxiety, and hostility in many ways. These include clinging to his parents or ignoring them, eating or sleeping poorly, undergoing treatment procedures with unusual stoicism or struggling against them, showing great fear of treatments, remaining silent and withdrawn, or responding with anger to friendly overtures.[201]

The child's anger may come from many sources, but there is general agreement that he typically views hospitalization as a form of punishment or rejection. He may blame himself for his illness, and feel he is being rejected or punished by his parents for the illness or other things he has done.[51, 201]

The feeling that hospitalization is a result of parental rejection may come from a child's belief in the power of his parents:

> Ordinarily the world of the young child is very much controlled by the parent. While loss of control may threaten the parent, it destroys a basic "truth" of the child's world—the truth of omnipotence of the parent. Small wonder that it is often easier for the child to blame the parent for his hospitalization than it is for the child to restructure his concept of parental potency.[201]

To counteract the child's feelings, caregivers and parents should be aware of his concerns, even though he may not be able to articulate them. If he is able to express his feelings, he should be encouraged to do so, even if those feelings are negative. Treatment centers can alleviate a child's separation anxiety by allowing him to have his mother with him and encouraging family members to visit. Caregivers may assist both parents and the child by providing guidance on how to ease common fears, which the child may or may not be directly expressing. For instance, parents can be encouraged to emphasize through both actions and words that they are not angry with the child, that they love him, and that they too are unhappy that he is ill and cannot be at home with them.[51]

Young children with cancer who cannot express themselves have sometimes been overlooked in attempts to provide psychosocial support. Play therapy and patient activity groups can be used for this purpose. They provide an opportunity for children in hospitals or clinic waiting rooms to use their energy in productive ways and to interact with other children while undertaking an activity natural for their age group: playing. Parents and siblings may be encouraged to attend these groups.

In some hospitals, such groups are primarily diversional. Here, a special room or area of the inpatient section and clinic are equipped with playthings—toys, books, games, record players and records, materials for painting and drawing pictures, even a piano or electronic games. Within this setting, children may interact with other patients and with siblings under the supervision of treatment team members. At the same time, the caregiver is able to observe and listen to the child and can pick up clues to his concerns, which might be talked out on the spot or passed on to other members of the treatment team.

Another approach is a play therapy program designed to help children assimilate their feelings about hospital and treatment experiences and place them in a context appropriate to their age and understanding. Here, playthings and activities are designed to provide opportunities to reenact and master the anxiety associated with their illness and its treatment.[4] Conventional toys are replaced or supplemented by hospital equipment such as syringes, needles (with the sharp end clipped off), I.V. tubings, suture sets, surgical masks and gloves, stethoscopes, bandages, and alcohol swabs. Puppets and stuffed dolls (which may represent children, parents, and treatment staff) can be used for role-playing and given injections, I.V.'s, and surgery. Supervised play with hospital equipment may result in improved adjustment to medical procedures by allowing children to express feelings of anger and frustration at treatment personnel and to gain a sense of mastery over the situation through greater understanding of procedures.[4] It also allows caregivers to uncover misconceptions the children might have and to correct them. A typical case is the 5-year-old who said to his puppets, "I told you not to hit your brother. Just for that, you're going to get a shot."[4] Having observed this incident, playroom supervisors were able to explain that people get injections because they need medicine, not because they need to be punished. Caregivers may also use other techniques, such as body image drawings and murals of the clinic and hospital, to work with the children.[106]

Play therapy offers children diversion and allows caregivers the opportunity to observe behavioral clues.

Such programs require trained personnel who can supervise and direct the child's play and recognize feelings the child is expressing, even indirectly.[4]

SUBSEQUENT TREATMENT

In most cases, the child will be released from the hospital before treatment has been completed. He can then return to his family, but often he still must go to an outpatient clinic for additional treatment at regular intervals. Thus, release from the hospital for most children with cancer does not mean resuming their former way of life. The child is still ill, treatment continues, and a new lifestyle for the patient and family begins.

For the parents, taking home a child recently diagnosed with cancer can be frightening. "In the hospital someone else is responsible for this newly conceived person—their child with cancer—and parents frequently feel unequal to the occasion." [59]

Caregivers can ease this situation by being sensitive to it. If medication is to be taken at home, the parents should be given written instructions, along with telephone numbers of treatment team members and ways to obtain information after regular working hours. Parents should be encouraged to call with their questions. The family physician or pediatrician should be informed about the patient's status frequently so he can respond to the parents' questions. (This is especially true for out-of-town families.) At the hospital, before the child's release, specific information on the return appointment should be made clear and the family shown the outpatient area. Registration forms for the clinic can be completed early to ease the first outpatient visit.[59]

Many treatment centers routinely make contact a few days after the child's discharge.

This may be done by telephone or a home visit. The contact reassures the family of the treatment team's continuing interest and support. As more and more patients are being treated on an outpatient basis early in treatment, there is a growing need for such support.

Home visits can uncover vital information, including whether the parents understand the disease or are confused about some aspect of treatment. The visitor also has an opportunity to observe the parents' interaction with the child, and can see if they are being overly protective or overly permissive.[47]

Because treatment often takes place in a clinic setting, families and patients must now adjust their lives around clinic visits. This involves scheduling other aspects of their lives to fit the appointments, obtaining transportation to and from the clinic, and waiting at the clinic, sometimes for hours.

For families whose homes are in other cities, treatment regimens that require daily clinic visits cause housing problems. Programs to ease these problems have been established in some cities.[50] Houses are provided near the clinic where a parent (usually the mother) and the child can stay during the course of treatment. Cooking facilities are available and the child may be cared for by his mother instead of being hospitalized when it is not necessary. The child and parent may also draw support from other families in the same situation and from out-of-town parents whose children are hospitalized.

One such facility is the Ronald McDonald House in Philadelphia. Here, the proceeds from the sale of certain food items donated by regional McDonald operators, contributions from philanthropic organizations, and donations of labor and materials from parents of sick children have been used to create a guest house for out-of-town families of patients being treated at a nearby hospital (see *Appendix A*, "Support Programs"). The guest house contains seven suites, each designed to accommodate a family. If just one parent has accompanied the child, a suite shared with another single parent is available. Rates are reasonable, far below those charged by hotels and motels, and occupants are encouraged to use all the house facilities (playroom, kitchen, laundry, etc.). But more important, the house provides emotional support to people in a strange city under the strain of a trying experience. As the "housemother in residence" says: "The moral support is the biggest comfort their being together can bring. It's often, I think, what keeps a family from cracking—when they know everyone is pulling for them."[158]

The clinic experience is no more natural to the child and his family than was hospitalization. In addition to the problems created by being in a new setting with new demands, it serves as a continual reminder that the child is sick and requires treatment.

One study of leukemic children between the ages of 6 and 10 who were in remission and being treated in an outpatient clinic found that the children realized theirs was no ordinary disease.[206] Testing methods showed these children to have a greater preoccupation with their illness than a control group of chronically ill children with similar hospital experience. Although the chronically ill children eventually seemed to adapt to the clinic visits, the leukemic children found such visits increasingly anxiety-provoking as time went on.

In observing parents and children in a clinic waiting room, one group of investigators found the atmosphere tense and depressed, the people silent and immobile.[86] Parents and their children rarely separated, with little interaction taking place among children or parents. Conversations with parents brought out information on practical problems associated with the visit:

> Occasionally, parents alluded to the strain caused by the long waiting time, the traveling, the build-up of tension within the child during the week preceding the appointment, restive or uncooperative behavior on the part of the child with respect to clinic attendance, and other unpleasant factors surrounding the clinic visit.[86]

The investigators found an atmosphere similar to that described in a study more than 15 years earlier, where both mothers and children disliked clinic days and children did not play or interact with one another, but instead stayed close to their mothers.[28]

Noting that parents and children were handling their problems internally and without support, the investigators devised a program to help them cope with the clinic situation and the larger issues raised by cancer.[86] The children's passivity was felt to result from an overwhelming sense of being sick and vulnerable, brought on by the fears aroused by being at the clinic. Because of the clinic's focus on the child's illness, separation anxiety (particularly in relation to fear of hospitalization) and mutilation anxiety (in response to medical procedures) were high. To overcome those anxieties, a play group for children was established. In addition, parents were encouraged to talk with other parents or a therapist about concerns they would not express in front of their children.[86] The investigators found that play and communication helped the children and parents express and master their anxieties.[86] Play groups in clinics may be similar to those operated for hospitalized patients, providing an outlet for children's energies, as well as allowing them to express themselves.

Another author noted that anxieties can be eased by giving special attention to the clinic.[59] A pleasant waiting room with toys for the children and activities supervised by the staff can make it a more enjoyable place. A room with a bed and a crib for patients who need transfusions or prolonged treatment is necessary. In one program, the sick child's brothers and sisters are invited to come to the clinic and play with the children waiting for treatment.[226] In this way, siblings can share some of the child's experiences.

TREATMENT AND SIDE EFFECTS

The child with cancer must live with the side effects that accompany treatment. He should be informed about possible side effects and told that they may alter his physical appearance and cause pain, weakness, and illness. They may limit his activity and remind him that he is different from other children. Although any side effect may create problems with a child's self-image, this is particularly true when they are noticeable to others.

Nausea and chronic vomiting from chemotherapy are almost always present. Patients may even develop "Pavlovian style conditioned reflex vomiting. In such instances a child may begin to vomit the day before a scheduled treatment or become nauseated simply by thinking about the hospital or clinic." [107] Relaxation training and suggestion or hypnosis are sometimes useful in treating such reactions in children.[68]

Because of the increased risk to infection children on chemotherapy face, their parents must be particularly careful to guard against exposure to infections. This adds to stress and may encourage tendencies to overprotect the child.

The fact that most side effects from chemotherapy appear to be reversible may be little comfort to the child and his family while they are occurring. The nausea, pain, hair loss, or other side effects become a part of the child's life and may limit his ability to participate in normal activities at a time when he desperately wants to be normal.

The side effects also become part of the family's life, for the family must try to help the child live with the effects of his medication. Handbooks providing information on ways to minimize certain side effects and listing those that should be reported to a physician are available and may be helpful to parents.[34, 193] The child's physician or another treatment team member should tell parents what to watch for if dangerous side effects are possible.

The pain and sickness are very real problems with which the child must cope, and so are the emotional problems that accompany the side effects. In some cases,

> the child often has to adjust to a changing body image—gaining weight on steroids, then losing, only to gain again in a few months when the treatment protocol demands steroids again. The same is true for hair loss. These body image changes are particularly difficult for the older child and adolescent to face and may become so unnerving to the child that he wishes to terminate therapy because of his constantly changing body image.[120]

There is a noticeable lack of information in the literature on a child's reaction to surgery. However, it seems safe to assume that children share with adults a fear of surgery and feelings of loss and mourning for the part of them that has been removed.

Children can be prepared for surgery by visits to the operating and recovery rooms, and by meeting and talking with the people who will be present at their operations. These people tell the child what they will be doing during the surgery and how they will look. They can, for instance, bring along a surgical mask and put it on for the child. This advance preparation can at least ease the shock and accompanying fear of the sterile operating room, strange equipment, and uniformed, masked personnel.

Children who have had an internal organ removed may feel a lack of wholeness.[221] Amputations of the extremities for bone cancers, primarily osteosarcomas, may produce similar feelings, and they also require significant adjustments on the part of the child in terms of accepting and learning to use an artificial limb. Caregivers may prepare children for the effects of amputative surgery by encouraging them to discuss their feelings and fears about the surgery and the loss of the limb, and perhaps by arranging for the patient to see and talk with another child who has experienced it and is doing well. Physical rehabilitation should begin early, and patients who are scheduled for amputation of a leg may even begin walking with crutches before surgery.

When surgery is combined with radiation therapy for central nervous system tumors, motor skills, developmental skills, and cognitive functioning may be affected. Appropriate treatment center personnel should assess these factors when determining the appropriate educational situation for the child. Physical and emotional therapy may be required.[38]

There is also little information on the effects of radiation and a child's reactions to this form of treatment. Certainly the equipment and procedures must be frightening at first to young children.

Treatment centers might prepare a child for radiation therapy by giving tours of the radiation area and explaining the equipment. During this tour, the child should be shown that, although he must be left alone in the room for the treatment, caregivers are watching him and that they will leave him alone only as long as they must.

NUTRITION

Nutritional problems resulting from treatment are common in childhood cancer and are particularly upsetting to parents, who may find their efforts to feed the child frustrated by fluctuations in appetite and tolerance for food. Most side effects that influence a child's eating pattern cause loss of appetite and a resulting loss of weight. In general, treatment team members may help parents by encouraging them to be flexible and gauge their approach to feeding the child by his health or stage of treatment. They may point out to parents that different reactions to treatment may require different courses of action, and normal nutritional standards need not be strictly applied when the child is suffering from the side effects.

Advice and information from caregivers can help parents to see that their child eats as much and as well as possible under the circumstances. Treatment team members may also encourage parents to exchange recipes and ideas for making food more nutritious and appealing with other parents and to refer to books that address this subject in depth.[200]

4. REMISSION AND RECURRENCE

Patients and their families are often able to cope with the side effects of treatment and the resulting dislocation to their lives because the necessary adjustments are directed toward the all-important goal of remission or, if remission has already been achieved, remission maintenance.

When the child enters remission, the family and older patients may take heart that the disease has been controlled, at least for a time. Uncertainty about the length of the remission and fear of recurrence are common, however. Reactions among parents vary. Some worry excessively. Others stop grieving and even deny that their child has a potentially fatal illness.[118] The average parent probably falls somewhere between these two extremes, exhibiting both denial and fear at various points in the remission.

During a remission, particularly a lengthy one, family life resumes and normal patterns of sleeping and eating, work, and play are once again possible. The child's medical treatments to maintain the remission may become part of the family routine.[201] The child may return to previous activities, within any necessary limits set by his physician. School-age children can go back to school. The family members must now begin to consolidate their adjustment to

Although the child may be continuing maintenance therapy, remission should mean a resumption of family life.

the child's altered state, in which chronic uncertainty may be disguised by the happy, high periods of full remission.[84]

One relatively uncommon reaction to the child's return, labeled the "Lazarus Syndrome," occurs when the family has prepared for the child's death and mourned it, only to have the the child return to them through remission. This usually follows a lengthy separation, such as an extended hospital stay, where there seemed little chance of the child's recovery.[52] "If the child has been mourned realistically, he will find that his family left him and he has left it emotionally. As part of the mourning process, the family may have adjusted to a future without the child." [51] In such cases, it may be difficult to reintegrate the child into the family.

When a child has been in remission long enough for a physician to suspect that treatment is no longer necessary, therapy may be terminated. This is a difficult decision:

> No one yet knows the optimal duration, and the decision to electively discontinue successful therapy has become one of the most emotionally charged events of the entire treatment process. It means the end of a love/hate relationship between parents, patients, and chemotherapy. The nausea, vomiting, hair loss, painful injections, and interruptions of lifestyle are surrendered willingly. However, the comfort and security engendered by the successful treatments are difficult to risk, regardless of the rewards.[107]

A study of parents whose children had been successfully treated showed that the parents experienced a good deal of anxiety around termination of treatment: At that time, they had a number of concerns, including whether the disease would recur, whether it was safe to stop treatment, and whether the child was really well.[65] For some parents, this worry over recurrence continued for a number of years despite the absence of any evidence warranting such anxiety.

Treatment team members can ease that anxiety by offering realistic assurances about their belief in the therapy's success and its potential in the event of a recurrence. They might also schedule an appointment to meet with the patient and family shortly after treatment ends. This makes the separation from the treatment team seem less abrupt and provides an opportunity for family members to discuss any problems they are having in coping with the disease on their own. The team member who relates best to the patient and family might also maintain contact with the family, calling to schedule appointments for checkups or maintenance treatments, or just to chat about how the patient is getting along at home.

RECURRENCE

The first relapse is a blow to both the child and his family: "This . . . is always an event of enormous proportion and a cause of severe disappointment. Parents are usually able to tolerate subsequent relapses better although they continue to be upsetting experiences." [47]

Relapse forces the family and the older child with cancer to come to grips with the hard reality that he is still sick. Denying the seriousness of the disease is no longer effective and the fear of the child's death again becomes acute.

Relapse may make the child with cancer feel that all his efforts and pain have been in vain: "The child, who has been dutifully taking his daily medicine and submitting to painful I.V.'s and intrathecal medications because of the admonition that he will stay well if he complies, now doubts the entire process." [118] In adolescent patients, relapse may bring the first conscious struggle with the implications of their disease.[84]

Nevertheless, one author says that, in his experience, patients cope extraordinarily well during this time. They may exhibit

> transient depression, anger episodes, withdrawal. But almost always they are short-lived, the children and young people showing a remarkable courage, ability to talk about their disease and its side effects when such talk is appropriate or requested, and an amazing ability to tolerate pain and uncertainty.[84]

5. FOSTERING DEVELOPMENT

As more and more children are living with cancer, attention has turned to the question of minimizing its effects on their development. One authority feels that care of the child with cancer should be directed at producing a "truly cured child"; that is, one who is "mentally healthy and who can function at an age-appropriate level in society." [227] For this to be possible, caregivers must pay attention to the whole child: "If we do not . . . we may find a biologically cured child who has not developed mentally, and who has not learned the experiences a normal child needs to learn to be competitive with his peers." [226]

A child's development continues while he has cancer, and may in fact be accelerated by the stress of the disease. This possible acceleration makes the child's environment during illness especially important. The environment must "allow normal development during abnormal circumstances." [227] In a young child, time is precious because developing children have short periods to master specific skills. Loss of these opportunities may slow development. Older children may need guidance in developing realistic career and life goals.[225]

Producing a truly cured child requires a special attitude on the part of caregivers, where each child is approached as a person who might die, but who also might live.[225] Caregivers must expect cure from the beginning and work toward fostering development.

When caregivers do not expect cure, they often contribute to retarding development. Some may expect the child to die and therefore not do what is demanded to help the child develop. This attitude, labeled "psychological euthanasia," [227] may protect caregivers. When they expect a child to die, his survival is a victory; if they expect him to live, his death is a defeat. In expecting children to be cured, caregivers may be hurt because not all children will be cured. But without that expectation, none will be truly cured.[227]

Children with cancer need to be accepted as they are, not as we would like them to be.[226] Adults may tend to either focus on the cancer or pretend it is not there. Either approach may result in an environment that is counterproductive to development: "To take the cancer away from the child is to deny that child a major aspect of his reality. To focus on the cancer only is to deny the child his normal world." [227]

Increasingly, attempts are being made to give children with cancer developmental experiences as similar as possible to those of other children. This can be done within limits, even in the hospital. But an effort must be made to do so. As one physician admits, "If you want hospitalization to be a plus situation instead of a minus, you have to work at it." [236] Recent changes in hospital rules outlined earlier in the chapter on treatment show that some hospitals are working at it. In terms of emotional support, many of these changes allow the child to maintain the sources of strength he has come to depend on and help him face what he must. Other innovations, such as play groups and outings, allow him to take part in normal activities even though his situation is atypical.

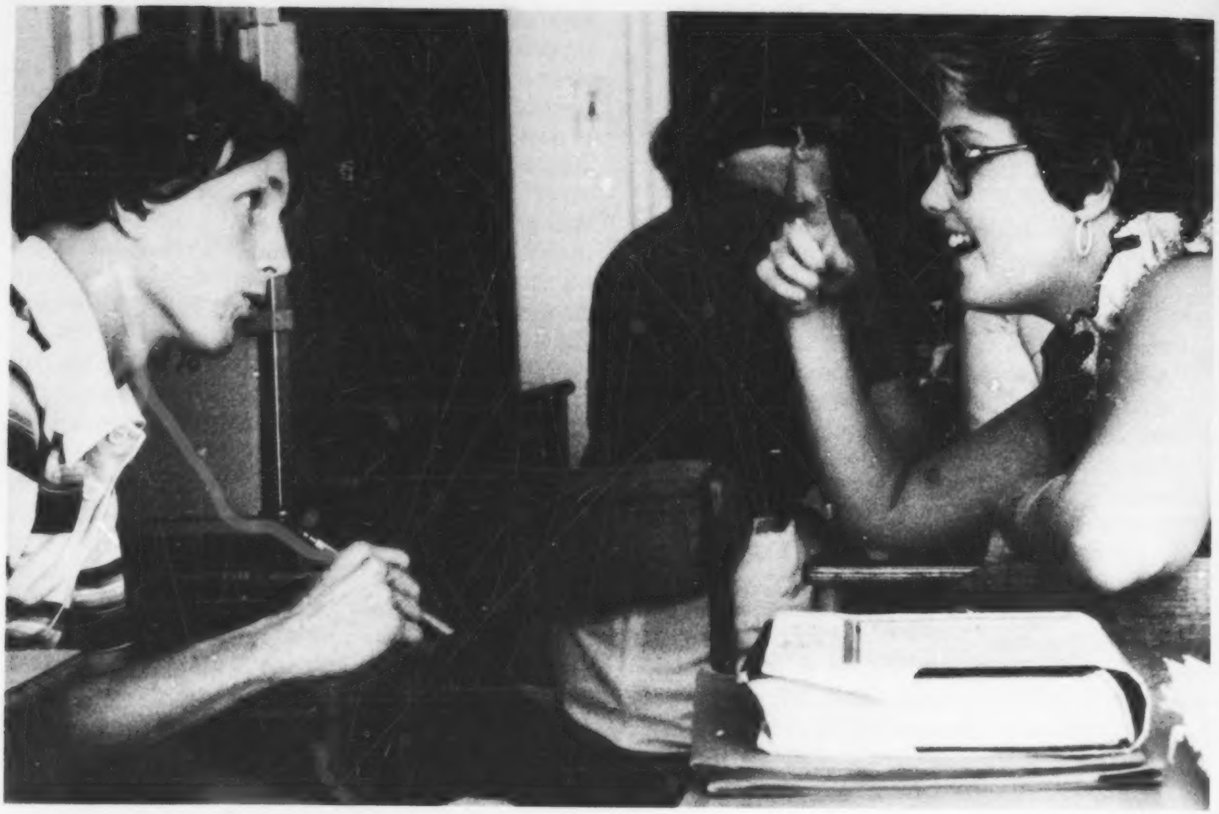
Maintaining discipline is important to any child's normal development. To give him a sense of well-being, a sense of social acceptability, certain behavioral boundaries must be set. In the case of a child with cancer, parents and caregivers alike must guard against the temptation to set too many limits through overprotectiveness or too few through overindulgence.

The impulse to overprotect the child with cancer may stem from the parents' fear that the child will become ill again. Overprotectiveness on the part of the caregiver

> may represent a conscious attempt to protect the child from further damage, especially with those children whose disease has produced sequellae, such as partial or total blindness or unsteadiness of gait, which realistically endanger the child in his daily functioning.[185]

It may also be an unconscious attempt to compensate for the anger parents and caregivers feel about the disease and its effects on the child. Aside from hampering development, overprotectiveness almost certainly makes the child angry at the people who are restricting his mobility, which has already been reduced by the disease itself.[185]

Paradoxically, overprotectiveness and overindulgence frequently go hand in hand. While limiting the child's physical movements, parents and caregivers may tolerate behavior they would not accept in a well child. Allowing the child to "get away with things," or buying whatever he asks for, can frighten the child by telling him that his disease is indeed serious: "He knows that only people who are not



School attendance by young patients is important for developing social skills as well as stimulating intellectual growth.

expected to live get this type of attention, and he may be feeling quite well." [118] Furthermore, the child may feel guilty because he is tyrannizing the people who are trying so hard to help him.[185]

Caregivers and parents must learn to strike a balance between the child's real needs resulting from the illness and the necessity of encouraging him to function as normally as possible.[192] Although discipline must be tempered with understanding, they must realize that:

> When the child meets overprotectiveness in one [person] and overindulgence in another, or both reactions alternately in one and the same [person], he is forced to cope with what is probably the single most corrosive element in his adult environment—inconsistency.[188]

While exercising some self-discipline themselves with respect to overprotectiveness and overindulgence, caregivers can help parents overcome these tendencies as well. A survey of parents of children with cancer found that two-thirds of the respondents felt they had discipline problems.[120] Over half attributed their problems to a lack of knowledge about what could be reasonably expected of the child, given illness and treatment effects, or to a lack of information on how to help the child cope with the illness. According to one mother:

> It's no coincidence that the sign of cancer is the crab. My son is so grouchy and difficult to deal with when he takes steroids I feel sorry for him because he is so miserable. I know he can't help himself and yet I know that certain behavior (aggression toward his sister) cannot be allowed. I often feel confused about what to let him get away with and when to set limits.[120]

Assisting parents with discipline problems is a difficult task. Nevertheless, caregivers can make a difference by giving the parents adequate information about the emotional as well as physical side effects of cancer, suggesting ways to cope with tense situations like giving medication to a child who does not want to take it, and tactfully intervening when parental discipline or the lack of it seems to be interfering with the child's development.

Since many discipline problems are basically socialization problems, caregivers should also stress the importance of continuing the school-age child's education. Besides intellectual development, school imparts basic skills in interacting with peers and authority figures outside the family. It is one of the main socializing forces in society and provides a common experience that extends over geographical and class lines. As one educator put it, "School is a major part of a normal child's life and the sick child can never approach normality in life style unless he is in school and is productive in the role of the learner."[44] Several forms of schooling are available to the child with cancer, depending on his condition and local resources.

HOSPITAL SCHOOLS

In hospital schools, children can continue their schoolwork while hospitalized. In such programs,

> children are expected to attend [the hospital] school on a regular basis, utilizing their books and schoolwork from their home school and working with accredited teachers from [the] local school district. If they are too ill to come to the schoolroom, then the teacher will go to their bedside.[235]

If textbooks from the home school are not available, individualized study is still possible by asking the home school to provide guidelines around which the hospital teacher can structure a curriculum.[102]

In hospital classrooms, it is possible for students to be studying at different levels and from different textbooks, but still have the advantage of classmates. This provides an opportunity for the child with cancer to discuss fears and concerns with others who share his experience: "Pupil interaction, peer tutoring, and group discussions about the hospital setting can ease anxieties and bring the patients together as students."[102]

Hospital school programs not only allow children to continue their schoolwork, they also establish an atmosphere of hope by giving children "the secondary message of expectation that they are going to do well and that when they do, they can be expected to carry on their normal schoolwork with as minimal disruption as possible."[235]

In general, a child's specific school situation will be established by medical staff and teachers. Time for school may be limited by medical considerations, which are given priority. When bedside instruction is offered, schooling may be tailored to treatment considerations, so a child may go to the classroom one day and receive bedside instruction the next.[102]

HOMEBOUND PROGRAMS

Treatment centers should be aware of and direct parents to homebound programs that will provide teachers in the home for the child with cancer who is not hospitalized but still unable to attend school. While these programs allow students to keep up their schoolwork they limit peer interaction and the development that accompanies it. Because of this, an appropriate member of the treatment team may work with the homebound teacher. The team member can encourage the teacher to minimize the cancer patient's isolation by having students communicate with one another over the telephone or in writing and above all, to see that homebound students are encouraged to work toward the goal of returning to regular school.[102] Homebound instruction can also be used along with regular schooling for children who are unable to attend school all the time.

RETURNING TO SCHOOL

Hospital and homebound programs are no substitutes for regular schooling, and the child with cancer should return to school as soon as medically possible.[106] However, that advice may not be welcomed by the child or his parents.

Children's attitudes about returning to school are influenced by their previous performance in school and their satisfaction with it, their attendance history, and their parents' feelings about the importance of schooling. Body changes brought about by treatment may also affect a child's willingness to attend school.

He may fear teasing and rejection by peers as a result of hair loss, weight gain, surgical scars, or skin discoloration.[243]

Parents may feel that the child has suffered enough without forcing him into school. Or they may seek to protect the child by keeping him at home, where they have control. For parents who believe the child will die soon, school may seem an unnecessary burden. Whatever the reason, the parents' reluctance to send the child to school often comes from their own feelings of guilt or fear of losing the child.

In severe cases, the child's and parents' fears may combine to produce school phobia. This condition is characterized by the child's refusal to attend school, fear of separation from the mother, and somatic complaints.[119]

To prevent problems with school attendance, the treatment team needs to take an active role. Encouraging the return to school early in treatment sets the stage for successful reentry. Discussing potential problems with parents and children helps them to anticipate and deal with these problems when and if they do arise. Continued encouragement of schooling during clinic visits reinforces education as an essential part of the child's life.

Once the child does return to school, his education is complicated by the disruption to life that accompanies cancer. Absences from school may be caused by hospitalization, outpatient visits for treatment or checkups, or illness related to therapy or increased vulnerability to other ailments. Even when the child is able to attend school, his performance may be lowered by physical effects that interfere with energy level, mental development, and physical activity.[243]

One study of the school experience of long-term survivors showed that the nausea, vomiting, and fatigue that frequently result from cancer and its treatment decreased patients' energy levels and ability to participate in physical education and academic classes. Study subjects said fatigue caused difficulty in concentration and increased the time needed to complete schoolwork. For one-half of the study subjects, physical education was either limited or they did not participate at all.[243]

In some cases, a child's disease or its treatment can affect the central nervous system and reduce perceptual-motor, sensory, reasoning, and intellectual activities. In the case of brain tumors, such effects can be severe.[13, 158] Recent studies of children receiving irradiation of the central nervous system also point to a possible negative effect on intellectual functioning.[54, 55] And a study of the effects of chemotherapy on the central nervous system indicates that it, too, may adversely affect intellectual functioning.[144] Future research in this area will more definitively establish how such treatment forms affect intellectual development and function.

The unique situation of the child with cancer places special demands on teachers and other school personnel. Contact with and support from the treatment center can assist them in meeting these demands. In a sense, teachers and the schools become part of an extended treatment team whose goal is seeing that the child's development continues despite all the factors against it. School liaison programs have been started at many cancer centers. The following is a description of such programs, drawing on published accounts[75, 99, 106] and conversations with treatment center personnel.

In many programs, a treatment team member acts as the school liaison and contacts the teacher before the child returns to school. Permission from the parents and child is usually sought before making contact. Teachers and other personnel are given information about cancer and the child's condition, including any limitations imposed by the disease or treatment, upcoming clinic visits, and possible reactions to treatment. Questions from school personnel may be answered and their attitudes and those of the child's peers discussed. When a personal visit is not possible, perhaps because of staff limitations or the distance between the school and treatment center, contact can be initiated and maintained by telephone or mail.

Continuing contact with the teacher provides an ongoing opportunity for the school liaison to answer questions as they arise and to provide reassurance and advice to the teacher. Because teachers may find the availability of someone with whom to discuss their plans and feelings particularly helpful, they should be encouraged to contact the school liaison whenever they need to. On the other hand, if the treatment team becomes aware of problems that make the child reluctant to continue school, the school liaison should contact the school to discuss the situation and possible solutions.

The teacher and school liaison may also want to consider making classroom presentations about cancer. This can be an effective way of answering classmates' questions and countering any misconceptions they may have about the child's illness.

The treatment center's work with the teacher is vital, because teachers in particular can help the child adjust to school and can influence the reactions of classmates by helping them understand the disease and preparing them for any physical changes or limitations in the child. To do this, the teacher must understand the child's condition and must be able to deal with it honestly.[102] Through contact with teachers, the school liaison can not only provide information, but also help them come to grips with their own feelings about cancer. These feelings must be dealt with before teachers can work successfully with the child with cancer—a child who may fear desertion and may need positive reinforcement to maintain a strong self-image.[45]

Experience has shown that teachers may not always be prepared for this task:

> With few exceptions, however, this experience is a new one for the teacher. She feels the demands of the situation, but she doesn't know how to respond. She has many questions, but she doesn't know who can answer them.[75]

Without support from the treatment center, schools may be forced to deal with the child with cancer without a great deal of information. One workshop for school personnel showed that parents were the primary source of information for teachers, with the medical center and local physicians supplying information less than 5 percent of the time.[106] Teachers were found to have several primary concerns about having a child with cancer in their class. These were: the child with cancer or other students would ask questions the teacher was not prepared to answer; the child would become seriously ill in the classroom and adequate first aid or assistance would not be available; the child would be exposed to colds from other children; and the child would learn something about his illness that his doctors and parents had not told him.[106] Outreach from the treatment center can alleviate these fears by providing information, guidance, and support. Caregivers may wish to provide teachers with relevant materials, or direct them to other sources of such information.

Teachers may also be unsure of how much to expect academically from the child with cancer. The study of the school performance of long-term survivors found that

> 39 percent of the patients were given higher grades than they earned or were "passed" to the next level because they had cancer. This failure to require reasonably expected performance, academically cripples the child and leaves him with educational deficits.[243]

Being judged on a different set of standards than their peers can also enhance feelings of inadequacy and isolation in children with cancer.[99]

Treatment center staff can help both the teacher and the child by informing teachers that, although some of their activities may be limited for medical reasons and they may require time to make up work missed during treatment or illness, children with cancer who are attending school need to be treated as normally as possible.

Most programs focus attention on the teacher of the child with cancer, but other personnel, such as school nurses and teachers of the patient's siblings, may also require assistance. Treatment center staff can assist school nurses by providing information on the child's specific condition and any needed updates on childhood cancer in general. This procedure enables nurses to provide assistance to teachers and accurately answer their questions. Teachers of siblings should be made aware that the patient's cancer affects the entire family and that they should look for and report behavior changes in their own pupil. Furthermore, they may be able to help siblings answer questions from classmates.

Whether or not a formal school liaison program is established, caregivers, parents, teachers—even classmates and siblings—must treat the child with cancer as if he will do well. The children and families who benefit from efforts to make patients' lives as normal as possible are not only those for whom treatment is successful and who are now cautiously labeled as being cured. Those whose lives are lengthened by treatment even though that treatment ultimately fails also benefit. For while they live, they are allowed to be with their families and peers, to experience, and to learn. As one parent of a child with leukemia put it:

> Parents need to prepare their child to grow up and children need to feel they have a future. Many parents make the effort to take a child to Disneyland for a last fling, but don't make the effort to send the child to school and prepare for a future. The work of childhood is preparing to be an adult. If we take away the purpose of childhood, what is left is an empty space. Children need to dream of being married, having careers, raising children. *There is a difference between denial, and acceptance with hope.* Preparing a dying child for the future by sending him to school, giving music lessons, asking what he wants from life is making him like the "normal" kids, which is what he wants most of all. And if research continues, who knows—he may very well have that fanciful future.[192]

6. THE ADOLESCENT'S SPECIAL CONCERNS ABOUT CANCER

Adolescence is a special period, a time of transition. Although teenagers share many of the problems of childhood cancer, those problems take on new dimensions when added to the change and conflict that accompany adolescence. Just as adolescents are not

Teenagers with cancer, like all adolescents, can be part child and part adult. The special developmental needs of these young people are complicated by the limitations of their disease.

children, neither are they adults. Although old enough to understand the implications of their diagnosis and prognosis, they have not completed the personality integration or evolved the adult defense mechanisms needed to cope with cancer.[151]

The transition from adolescent to adult involves physical, emotional, and social growth. An adolescent's development may be seen as proceeding along a given course, and "although a crisis such as severe illness alters this course, the tasks and concerns of that developmental period still appear unchanged for the ill child." [212] Erik Erikson describes adolescents as "primarily concerned with what they appear to be in the eyes of others as compared with what they feel they are." [58] In the process, the adolescent must establish his independence from parents and other adults, adjust to sexual maturation, enter into mature relationships with peers of both sexes, and begin to prepare for the future.[81, 125, 229]

INDEPENDENCE

Adolescents with cancer have a need to assert their independence but they have an illness that imposes dependence. In looking at this aspect of adolescent cancer, it has been noted that:

> Prolonged medical treatment, particularly during hospitalization, contributes toward a shift in control from the adolescent to the institution and its staff. The process of reinforced dependence and regression is inherent in medically ordained periods of compliance and inactivity during which the adolescent is passive and has things *done to him*.[100]

As inpatients, adolescents may encounter an "insidiously subtle social pressure toward dependence and regression" if made to wear pajamas instead of street clothes, take their meals in bed, and abandon previous schedules of sleeping and waking.[100] Furthermore, the hospital routine often results in a loss of privacy—something adolescents especially value as a symbol of their independence, and thus their worth as human beings. In the words of one teenager:

> Doctors, nurses, come and go without knocking. Sometimes I wanted to close all my drapes. I felt like I was in the zoo.[98]

Forced into a dependent state, frustrated adolescents may rebel. It is not uncommon for them to refuse treatment, break hospital rules, miss outpatient appointments, or undertake activities they have been advised against. Although these reactions cannot be solely attributed to the feeling of dependency (fear and reluctance to appear different may also be present), it is clearly a key factor. Consequently,

> it is important that the physician foster the spirit of independence in the patient by giving him some responsibility in the control of his disease, even if this means some deviation from strict treatment protocol.[151]

Patients might be encouraged to wear street clothes, attend school, participate in organized activities, and eat in communal dining areas. They might also be allowed a limited choice of body sites for blood tests, injections, or I.V.'s.

In terms of staff convenience, hospitals may prefer early morning wakeups and treatment procedures. The teenager, however, may feel more comfortable with a schedule that conforms more closely with his life as it was before the diagnosis of cancer. Treatments expected to make the patient ill, such as chemotherapy or radiation, might be given during the evening. In that way, the adolescent can visit with friends and relatives or engage in other activities during the day, when he feels well.

Outpatient clinics as well can adjust their schedules to accommodate the needs of adolescents. Teenagers may prefer to receive treatment in the late afternoon or early evening to minimize disruption to school attendance and outside activities. College students or older adolescents who work may want to come in for treatment on weekends, particularly if temporary hospitalization is required. Sometimes postponing treatment for a short time may be necessary so patients can attend, say, a special school event. They may also need a little extra time to prepare themselves psychologically for treatment.

Making special allowances in hospital or clinic schedules and treatment procedures obviously requires some advance planning and a willingness to change. Nevertheless, everyone benefits from the resulting flexibility. Because the adolescent feels less helpless and frustrated, he may in turn be a more cooperative and reliable patient.

RELATIONS WITH PARENTS AND CAREGIVERS

Rebellion against authority figures is common in all adolescents, and no less so in adolescents with cancer. For these teenagers, physicians and other caregivers join parents as authority figures and targets of rebellion. Their rebellion may be increased by the feeling that parents and physicians are forcing them into the sick role, which carries with it connotations of weakness and being different.

The success of therapy may in part depend on how well the adolescent and physician relate. Adolescents resent dishonesty and distrust those who withhold information from them.[98] They must feel their physicians are trustworthy and honest, interested, and available to spend time talking and listening.[151] This sense of trust and interest is important because care of the adolescent, unlike that of the child, often involves direct confrontation with the patient. Diagnosis is a case in point. Although it is advisable to have parents present when the diagnosis is communicated, "a physician should never ask a parent to explain the diagnosis to an adolescent." [91] The teenage cancer patient is mature enough to be dealt with directly, and will undoubtedly ask questions the parents may be neither emotionally nor academically prepared to answer. Nevertheless, the parents' presence will lend much-needed emotional support.[81]

The relationship between adolescents and their parents is a complicated one. Although teenagers aim at independence, they have yet to achieve their goal. (This is particularly true for younger adolescents.) They may vacillate between the desire to be independent and the need to be dependent, resenting what they see as overprotective behavior by their parents at one point and appreciating the support and protection of their parents at another.[151]

Problems may arise when parents react to their teenager's cancer by trying to take care of him when they should be learning to let go. They may attempt to maintain their authority by focusing on specifics of the child's care that appear amenable to parental control:

> Eating, in particular, is often seized upon with a quasi-obsessional manner by even psychologically sophisticated parents, and it is not uncommon for power struggles to develop between the adolescent and his parents with regard to eating, and food.[100]

This battle of wills on side issues, if allowed to continue, can hinder the adolescent's adaptation to the disease and achievement of independence.[100] The health professional can intervene by expressing an understanding of parental concerns leading to overprotective or overindulgent behavior while supporting the adolescent's efforts at independence.[151]

Caregivers and parents alike should be sensitive to the fact that patients may feel guilty about the extra burden their disease has placed on their families: One study found adolescent patients to be "concerned about the cost, the loss of parents' time from work and spoiled plans such as missed vacations." [125] A common goal for adolescent patients was getting a driver's license, thereby relieving the family of the responsibility for driving the patient to the hospital.[125]

BODY IMAGE AND PEER RELATIONS

Physical changes brought about by the illness or its treatment may result in major shifts in an adolescent's self-image, "hindering the development of new peer relationships and upsetting pre-existing social relations." [100] In adolescence, peer relationships play a crucial role in developing independence and learning coping behavior. It is possible that adolescents with cancer create their own sense of isolation from their peers. Negative self-perception and pessimism prompted by cancer may make teenagers reluctant to tell their friends about their illness.[125] "At an age when 'belonging' is so important, the feeling that he is not like others because of the defect that his illness represents to him produces a feeling of inferiority and loss of self-esteem." [151]

A study of adolescent cancer patients shows the effect cancer and its treatment can have on sexual and other peer relationships. In 15 of the 17 patients studied, the disease or its therapy produced a major physical change that added to the normal stress of sexual maturation.[125] Among the physical changes noted were obvious tumor masses, loss of limbs through amputation, scars, and hair loss.[125] None of the patients had a serious relationship with a member of the opposite sex, and for most, even relationships with peers of the same sex were strained. Only four patients appeared to have maintained normal peer relationships.[125]

Although teenagers strive for independence from their parents, young patients still appreciate parental support and understanding.

When embarrassment over physical changes causes withdrawal from previous social activities and refusal to return to school, adolescents may undergo prolonged periods of depression.[100] In the study mentioned above, depression was found to be the major psychological effect of the cancer diagnosis.[125] Nine patients communicated this directly to staff, while the behavior of four others was judged to be evidence of depression. Seven of the depressed patients expressed their emotional state by refusing to accept all or part of the prescribed therapy; another three frequently missed appointments. Reasons for refusing therapy included fear of discomfort, but the major cause was the feeling of worthlessness: "Even if I am cured, I'd think of myself as a deformed person." [125] Most patients eventually agreed to take treatment—not to help themselves, but because of the people who loved them.

PREPARATION FOR THE FUTURE

As part of the maturation process, adolescents normally look forward to what their lives will be like in the future. Most begin thinking about education, careers, marriage and children. The adolescent with cancer, however, may be concerned about whether his disease will limit the possibilities open to him. It is true that school or employment may have to be interrupted for treatment. Further, sterility is a possible side effect of some treatments. Older adolescents may see their friends getting married and having children, and wonder if they will be able to do so as well. They also worry about the effects of cancer therapy on the children they might have:

> A 16-year-old girl with reticulum cell sarcoma achieved remission on radiotherapy and chemotherapy. She married when she

> was 19 years old and became pregnant. Shortly after this she sent us a letter containing the following questions: "What will be the effect of my disease on my pregnancy? What will be the effect of my pregnancy on the disease? What will be the effect of radiation therapy on my pregnancy? What will be the effect of chemotherapy on my pregnancy?" [151]

These questions are not easily answered because the long-term effects of cancer therapy are not fully known. A recent study concluded that "most young girls who are effectively treated with current regimens for childhood leukemia have an excellent prognosis for normal pubertal progression and reproductive function." [203] However, an important factor in that prognosis is the degree of pubertal development at the time of diagnosis and treatment:

> Normal sexual development correlates best with pubertal status at onset of leukemia; only 1 of 17 patients with diagnosis before puberty experienced altered pubertal progression, whereas abnormalities appeared in 6 of 18 with onset during puberty or after menarche.[203]

Another study examined the genetic effects of systemic chemotherapy and gonadal irradiation on the children of childhood leukemia survivors. It found that "the offspring have been free of cancer and other major chronic diseases. Under conditions of the study, no excess inherited defects were detected." [128] Still, both study populations were small, 35 young women in the first and 46 patients (17 males and 29 females) in the second. Both study authors note the need for larger samples and longitudinal data. Furthermore, "data are not available on genetic effects in man of newer cancer chemotherapeutic agents or drug combinations in current use." [128] Perhaps the best that can be said at present is that, although some study results are promising, cancer treatment may have an effect on sexual development and future progeny. But that may be little reassurance to the teenager looking forward to marriage and children.

In spite of the uncertainty about his future, the adolescent cancer patient must be encouraged to make realistic plans. Without them, he may withdraw, regress, and become depressed.[100] The responsibility of caregivers and parents is to provide the emotional support and information needed to make sound decisions. Certainly it must be emphasized that, with modern treatment techniques, young people do survive and do go on to become productive, socially acceptable adults. For example, a medical record review and questionnaire survey of 142 young adults (aged 18 and older) who had cancer as children revealed:

> Seventy-four patients (52 percent) had major defects in treated organs, while 17 (12 percent) developed secondary primary neoplasms (10 malignancies and 7 benign tumors). Despite these disorders, most patients had fully active lives. Eighty-six (61 percent) had attended college, and many were employed as professionals and managers. Seventy-five (53 percent) were married; 46 had progeny. Disabling psychological illness attributed to cancer in childhood was uncommon. These findings indicate the potential for high quality of extended life for most survivors of childhood cancer.[129]

HELPING THE ADOLESCENT COPE

Denial is a frequent coping mechanism employed by adolescents with cancer. Adolescent denial may be extremely aggressive, and patients may appear full of energy, omnipotence, and certainty. They will "beat" the disease.[100] One study of adolescents on research drugs whose cancers had failed to respond to conventional treatment found that, before treatment, patients displayed an inordinate degree of hope in the remission-inducing potential of chemotherapy. Their optimism dropped after treatment altered their physical well-being.[213] Nevertheless, in the beginning, 19 out of 20 interviewed thought they would make it, even though the odds were against them. Similar reactions are common to adults, but they may be more pronounced in adolescents, who, by virtue of their youth and previous good health, may regard their bodies as indestructible.

Denial is part of the normal adaptive process for many adolescents.[100] Furthermore, encouraging adolescents to continue as many prediagnosis activities as possible amounts to tacit approval of some denial as a valid way of adapting to the disease, because it enables them to function on an equal basis with their peers. Denial can become a problem if it impedes the treatment process or allows a patient to participate in activities against medical advice.[151] However, when denial means that adolescents continue to hope for recovery, even when faced with serious setbacks, it should be supported.[98]

Other coping mechanisms include overcompensation, intellectualization, and anger. Overcompensation or attempts to outdo peers, when successful, may reinforce denial and support the adolescent's belief that he is normal. Intellectualization may be used in an attempt to master anxiety by repressing the emotions involved with cancer and emphasizing the rational aspect of its existence. Teenagers using this defense tend to research their illness and ask many questions. As with other adolescent cancer patients, these questions must be answered truthfully but hopefully. Anger about the disease may be displaced to parents, siblings, or friends, but most often it is directed at caregivers.[101] Difficult as it may be, the object of the patient's anger must try to accept it as a normal reaction to cancer and refrain from responding in kind.

Psychological support for adolescent cancer patients must take into account their developmental needs. It must also be recognized that adolescents frequently have problems communicating with adults in general, and particularly their parents. Caregivers might be able to help parents and adolescents get over the hurdle of talking about cancer, if that is the problem, by encouraging open discussion of the disease and its treatment.[98] Because adolescents are extremely peer-oriented, however, peer groups may be even more effective (see *Appendix A* for an example).

Such groups are most likely to succeed if the meetings are viewed not only as support mechanisms, but also as social functions. In this way, adolescents can discuss cancer-related issues if they wish without feeling compelled to do so. They can plan activities, such as parties or weekend trips, and enjoy the company of others who are like them and share many of their concerns.

V. Coping by the Family

Traditionally, the family has been considered the primary source of emotional support to those facing cancer. In the words of a young wife and mother: "I feel surrounded by monsters of disease and despair. Ralph and those who love me are like an inner circle; they form a protective band around me. Without them I'd be dead." [35] Although the ability to support the patient should not be minimized, recent perspectives regard the nuclear family not solely as the principal refuge for the sick, but rather as the unit facing the disease.[70] Cancer disrupts the lives of family members just as it does the patient's, and is a threat to the integrity and functioning of the family system.

The diagnosis and treatment of the disease produce changes in the family's accustomed structure, patterns, and roles—changes that call for a reevaluation of old rules and a new flexibility. Sexual roles are an obvious example. Despite the influence of the women's movement, men are still expected to be strong, decisive, and able to provide financial support. Hospitalization of a husband fulfilling these functions requires another family member to assume his role. That change is not always easy, and for some not even possible:

> Donald was the dominant head of his family when he began cancer treatment. His wife, Jane, had always depended on his decisiveness and deferred to his preferences. Their 14-year-old son was a quiet, studious boy. During Donald's protracted treatment, he became progressively irritable, withdrawn, preoccupied, and ultimately dependent on his wife. Jane was faced with the choice of asserting herself and assuming much more independence or of finding someone else to depend on. Unfortunately, she was unwilling to experience the anxiety and uncertainty of a new role and began turning helplessly to her son. He tried to take his dad's place by supporting his emotionally distraught mother but became depressed and began getting into trouble at school. Donald and Jane grew more depressed and finally sought professional counseling.
>
> Donald's physical illness and treatment required role changes within the family that each would not tolerate. Donald could not bear to be dependent on his wife and became irritable and withdrawn. Jane could not tolerate unfamiliar responsibilities, and their son experienced too much conflict to compensate for all the family changes. Donald recovered and the family balance was partially restored. But the major stress experienced by each of them could have been prevented. Their difficulties arose from the vulnerability of their family system, their lack of understanding, and their inflexibility, much more than it did from Donald's cancer treatment.[35]

Clearly, caregivers need to understand the family's interaction if its members are to be assisted with the cancer experience. The health care team can assess financial and emotional roles and adaptation patterns by observation, by talking with the patient, or ideally, by meeting with the entire family to discuss the diagnosis and its impact. Exact timing and circumstances vary, but contact should be established early.

Contemporary caregivers regard the facilitation of communication as the key to family support and counseling. And patients themselves see the lack of candor as a problem. When one study asked 136 respondents to indicate their major problems from a list reported by other cancer patients, the second most frequently reported problem was the absence of open communication within the family. It was mentioned as often as physical discomfort and more frequently than difficulties with medications or overall treatment.[74]

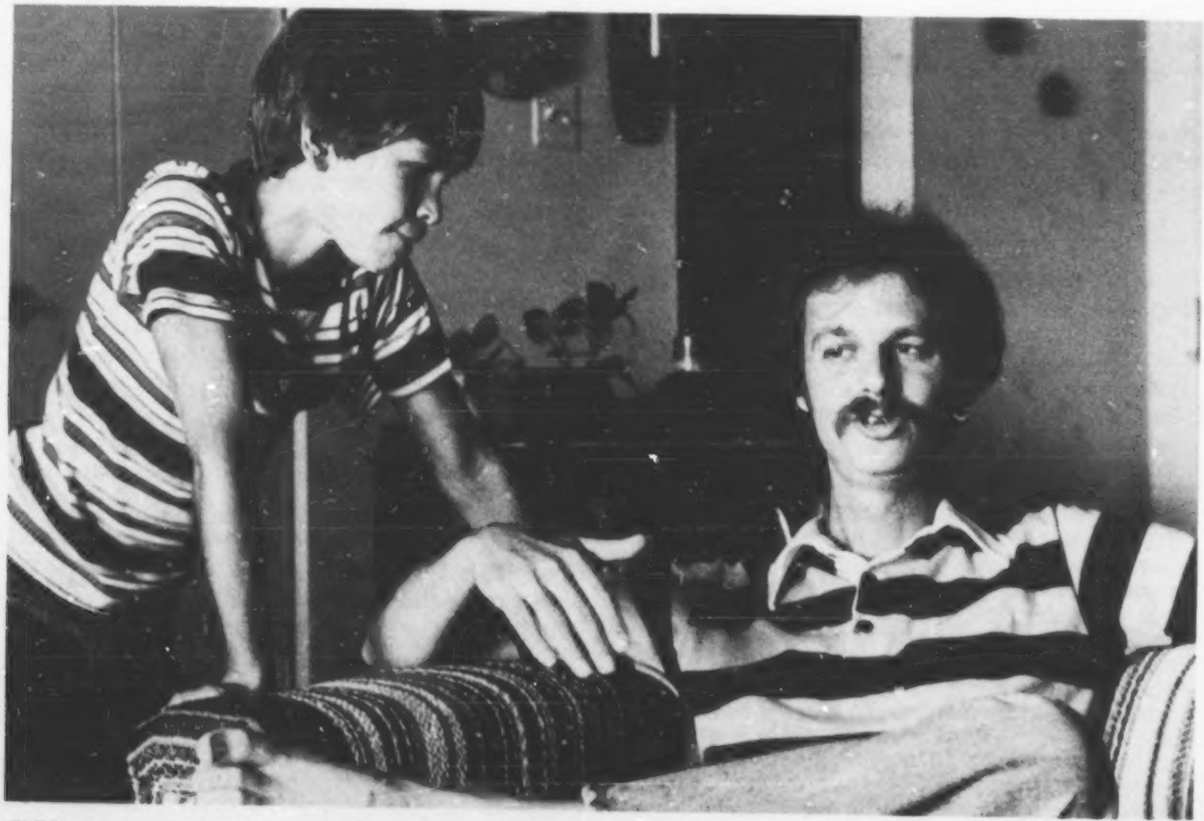
Discussion of emotions between patients and family members is often difficult. Some have never developed the habit, and some are inhibited by the cancer-imposed situation. One barrier is the natural, almost instinctual, need for families to protect the patient (and others) from the realities of cancer. The consequences of not telling the diagnosis have already been examined earlier (see the Diagnosis sections in Chapters III and IV). Other communication barriers may occur later in the disease, when patients may conceal their true emotions to avoid upsetting family members, particularly those thought to be already overburdened.

Family members may have vast discrepancies between their outward behavior and their inner feelings. Like most people, they feel it is important to be cheerful and optimistic when dealing with a sick person. The facade may conceal quite different concerns, however. Physical changes in the patient from surgery or treatment-induced hair and weight loss, for instance, can give rise to varying degrees of aversion. Families may also be disconcerted by changes in the patient's behavior, such as regression.[16] Feelings of anger, sadness, and depression over what is happening to the patient and concern for his future may be intense empathetic and sympathetic reactions. These negative feelings—although they are directed at the situation, not the person—are difficult to express. Guilt about having such feelings may be another barrier to communication.[241]

In considering the effects of cancer on the family, the children of cancer patients should not be overlooked. Whatever their level of knowledge or ability to comprehend the meaning of cancer, children are aware that a tremendous change has occurred in the household. Repeated absences of the patient for hospitalization or treatment, preoccupation of the well parent, and disturbances of their daily routine are obvious signals for the child who has not been told about the disease.

A recent study of children in families with one well parent and one advanced cancer patient examined the impact of the illness on children of all ages.[33] At the time of the study, none of the parents had died, and many of the findings are transferable to a chronic illness situation. Some of the study families exhibited extraordinary strength:

> Mrs. Eisler is a woman in her 40's, well educated and a professional person. She has



Children of cancer patients are quick to perceive familial stress and worry about their parent's illness.

> good personal insight, calls herself a "tough" mother. Her three sons are in their 20's, living at home and going to college. There is one 16-year-old daughter. Despite the fact that a very ill Mr. Eisler was being cared for at home, chaos was never permitted. Routine for each member of the family was planned: all ramifications of the illness were shared, and the children lovingly participated in the care of the patient. At no time was it unclear as to who was running the household. Despite the fact that the 16-year-old girl wished to participate as much as her brothers, Mrs. Eisler was careful to protect her from too much responsibility and quick to recognize that the daughter's sudden facial skin eruptions might be psychogenic. Mrs. Eisler offered her daughter counseling services if she wished but did not push when her daughter refused. This family has drawn even closer under the critical conditions.[33]

Others with "average strengths and ability to parent" did not fare so well. Dealing with their own feelings and attending to the medical and financial aspects of the illness appeared to take priority over parenting. The well parent who had assumed the familial function of the patient often found it too painful to offer children the truth in manageable doses. The study found an extraordinary amount of regressive behavior in young children (6 to 10 years old) who were kept unaware of the illness, compared with those who were told as much as they could understand. The quality of this communication was judged to be important in reducing children's stress; reassurance and love must also be transmitted.

On the other hand, adolescents in the study who were aware of the diagnosis exhibited increased behavior problems. As another authority has noted, cancer in a parent often creates an abrupt reversal of normal adolescent processes. Just as the young person is beginning a gradual emotional withdrawal from the family to establish individual identity, the illness forces intensified contact with parents. Some necessary role shifts—increased household or child care responsibilities—may be accepted by the adolescent. If parents convert adolescents to pseudo-partners and confidants, however, teenagers may act out their resentment by refusing to make hospital visits, drinking excessively, or using drugs.[231] Some respond to role shifts in quite another way:

> Tina, 18 years old, the oldest of three children, has just completed her senior year in high school. Since the illness of her mother she has taken over almost all of the family chores. She does some of the cooking, as well as all the washing and dusting. In addition to being an honor student and maintaining the household, she has worked on an after-school job and has been saving money for college. She appears self-sufficient and organized. Tina is very much like her mother with high expectations of herself and a belief that to show one's feelings and emotions is a weakness. Neither mother nor daughter believes in display of physical affection. Tina has attempted to work out her feelings around her mother's illness by doing a special science project on the subject of cancer. She does not allow herself to express her frustration, sadness, or anger. She has, to a large extent, stifled her emotions and feelings.[33]

Children in the study exhibited a variety of cues interpreted as a need for help. Caregivers might consider the same behavior as symptomatic of emotional disturbances calling for counseling: deteriorating school performance, physical and attention-getting symptoms (sleep disturbances or bed wetting), eating disturbances, acting-out or aggressive behavior, refusal to obey, expressions of hostility toward parents, and depression and tears.

Not all cancer patients and families need to be taught communication skills. Some solve their own problems or adapt to the cancer experience. Counseling and support by nurses and social workers can assist others. If family members indicate they are having difficulty, either by direct admission or by observed behavior, referral to a family therapy program (if available) may be indicated.

Caregivers might point out that family therapy, by addressing unresolved psychological and familial communication problems, can help all members cope with the situation and can enable them to draw support from each other. The following description of this counseling approach as applied in a cancer situation may be useful to caregivers.[39]

The first step when consulting with the family is a series of assessments. Developmental level—that is, the stage of the life cycle to which the family belongs—must be ascertained. Families with young children have vastly different needs from those whose children have grown and left home. The developmental age of family members is also important. Second, the therapist must determine the family's style, including moral and emotional patterns. Last, the family's previous patterns in times of stress

Counseling can help family members communicate among themselves and develop strategies to live with cancer.

must be explored. If these patterns are not appropriate to the stress of cancer, family members may be assisted in finding new methods of adaptation.

Family therapy can be effective only when there is communication between medical and psychological caregivers. Information obtained from each source should flow freely to the other for optimum benefit to the family.

Results of one multifamily group, led by a clinical psychologist and a nurse-oncologist, illustrate the value of this approach to family members and health professionals.[232] Although oriented to terminal patients, the group's philosophy applies to everyone with cancer: strengthening existing defenses and developing new strategies in living with the disease. Little time was spent on insight-oriented psychodynamics; instead, special attention was given to crisis intervention. The basic aims included: [232]

(1) Enhancing communication between the cancer patient and his family and friends;

(2) Enabling both the patient and family members to deal with their conflicts concerning serious or terminal illness;

(3) Working toward more direct and complete communication between patients, family members, and physicians;

(4) Providing information to the physicians and office staff to help them care for the patient.

Two observations made during the course of the sessions are particularly germane to caregivers. First, those families who experienced the greatest difficulty in coping had a history of long-term problems, especially in adjusting to life changes. Further, most felt they already used open communication patterns, but probing revealed they were unable to talk about cancer and its effect on them. Besides improving intrafamilial communication, the group received positive feedback from the physicians of the patients involved, who noted a "striking increase in the level of intimacy between them and the group attendees which greatly facilitated communication with these families and made the medical care of the patients more efficient and individualized."[232]

Outside the context of family therapy, health professionals, particularly nurses and social workers, are vital in providing support and helping families develop their own strengths. Support can be simple, and often consists of old-fashioned courtesy and thoughtfulness. Small gestures—giving a blanket to the family member staying by the bedside of a critically ill patient or patting a relative's shoulder—can sometimes convey more than words.[15, 16]

Relatives do not always ask directly for assistance, and caregivers should be alert for signs of stress and indirect requests for intervention. A genuine need for help may be obscured by "difficult" behavior, as was the case with the husband of one cancer patient. When his wife was transferred from her hometown hospital, staff members at the larger facility were warned of his demands and verbal abuse. He had rarely left her bedside and was distraught throughout the 6 weeks of her treatment. But social workers at the second hospital felt that exhaustion was a major contributor to his behavior and suggested that he go home every night. "Thank you," he replied. "No one ever told me I should do that."[70] Clearly he felt it was his duty to stay with her and needed "permission" to rest, yet could not express that need.

EFFECTIVE HEALTH BEHAVIOR

A look at what research has found to constitute effective health behavior, both in terms of interaction with the sick family member and family interaction with the health care system, can be useful to caregivers. One model, based on a study of 273 families, describes the "energized family" as a structure that may be effective in protecting family members' health.[174] While this may not represent the norm, neither should it be considered as beyond the realm of realistic family health behavior. The characteristics of the energized family are:

(1) Varied contacts with other groups and organizations in the community in an active attempt to cope and master their lives;

(2) Fluid internal organization, including flexible role relationships; i.e., sharing tasks such as housecleaning or sick care;

(3) Shared power, with each family member participating in decisions that affect him or her;

(4) High degree of autonomy within the family, and relationships among members that support personal growth.

When these characteristics are applied to dealing effectively with the health care system, the study authors generally propose an assertive role for family members during interactions with caregivers, including elevating the role of patient to professional consumer. Suggested courses of action are:

(1) Increasing the involvement of family members in medical management by establishing the family's role as part of the treatment team;

(2) Including families in the hospital care of the patient member;

(3) Increasing the home care of illness, in coordination with existing institutional facilities.

FAMILY MODEL

A useful aid in identifying potential problem areas might be a model based on an analysis of 100 families facing cancer.[70] The model describes the hurdles and offers a caregiver intervention goals at each point. As with any model, the stages described should not be misused to reduce human behavior to stereotypes. The stages are suggested guidelines and may not occur in the same sequence (or may not occur at all) for each family. The following discussion is based on this model, but also includes contributions from other authorities:

1. IMPACT occurs when family members learn of the patient's diagnosis, either by direct communication with the doctor or by being present when the patient receives the diagnosis. The shock and strain of the news may disorganize the entire family, or key members may assert themselves and assist others to cope.

   Immediate reactions are, understandably, bewilderment and anxiety. A common symptom is broken sleep patterns, with awakening every hour or two throughout the night. Sedation may be required to ensure adequate rest. Another reaction may be an attempt to escape, and some relatives find refuge in alcohol. Depression is also common, with underlying guilt for not having fully appreciated someone who may be taken away by death. Crying spells are not uncommon in men and women.[83]

The diagnosing physician may be the recipient of relatives' resentment, as if the diagnosis were somehow his fault. Anger is displaced to the messenger rather than the message.[191] At the same time, family members recognize that the physician controls the fate of their loved one.[88] Their investment in him may create a strained relationship, characterized by oversensitivity to imagined slights or by extreme compliance and politeness in an effort not to jeopardize the quality of care given the patient.

The goal of intervention is overcoming this despair and resentment by encouraging hope in all family members. Hope consists of two components: the feeling that the family can live with cancer and confidence that available treatment modes and new research advances will help the patient For some, hope is found in setting short-term goals such as going home from the hospital or returning to a prediagnosis activity. Health professionals' own confident attitudes can serve as an example and as a source of legitimate optimism for patients and families.

2. FUNCTIONAL DISRUPTION occurs as medical considerations, including time spent at the hospital, supersede family responsibilities. Role shifts may lead to problems in household management and meeting the daily needs of children. The hurdle facing family members is isolation, as family members are separated from one another in the fulfillment of disease-related tasks. Intervention should foster cohesion by defining needs and priorities and helping the family locate material and social assistance.

   Facilitating communications can also foster cohesion; if patients are not able to express their feelings openly to family members (and vice versa), conspiracies of silence may deprive each of mutual support. Working with the patient and family members to find means of helping and offering support to each other may open communication.

3. A SEARCH FOR MEANING is the attempt to intellectualize cancer and to find reassurance that no additional illness will occur in the family. Family members may turn to information materials or may analyze the patient's prior behavior to find a meaning or cause for the occurrence of cancer. This behavior leads family members to confront their own mortality, especially if they overidentify with the patient. Intervention should offer security and support so the family can maintain its integrity under the pressure of changing life conditions and overcome its vulnerability.

   Caregivers can and should help the family to learn about the disease by referral to booklets, brochures, and other materials. If information given by the physician is likely to be misinterpreted, forgotten, or confused, relatives might be encouraged to prepare a written list of questions leaving space for answers for future discussions.

4. INFORMING OTHERS may lead to questions family members cannot answer and the need to provide emotional support to people outside the family. Dealing with the emotional responses of others and rejecting unwanted advice before the family has had an opportunity to assimilate the impact of the diagnosis may cause the family to retreat from further contact with others. Intervention that helps family members sort out their feelings can provide the required courage they need to cope with outside influences.

5. ENGAGING EMOTIONS refers to the expression of volatile feelings as the family is changed by the illness. During this stage, family members may fear losing control if they display strong emotions. If these feelings are repressed, however, family members may lose touch with themselves and with others: "Loss of control, however, does not occur when people acknowledge and express their emotions." [70]

If the patient ceases to perform familial roles and is cared for in the hospital or at home, family members face two additional tasks:

6. REORGANIZATION is necessary to overcome the strain of multiple roles and new or additional tasks while a family member is seriously ill. A sense of cooperation may ensure that family goals are met and overcompensation by some members is relieved. Overcompensation by one member may lead to family conflict and competition. Equalizing tasks and consolidating resources can help promote family solidarity and shared responsibility for the care of the patient and the quality of family life.
7. FRAMING MEMORIES is the attempt to recall the ill family member before the diagnosis of cancer. Family members may find that their thoughts and dreams of the person with cancer revolve around episodes of the present illness. Attempts to visualize the person months or years ago in healthy, happy times fail, and waking or dreaming time focuses on the patient in various diagnostic or treatment activities. The abrupt change from the person's previous identity to "patient" influences the family's recall. As his sick role diminishes and the person's lifestyle becomes integrated into life with cancer, the family's recollections will expand to include all of his individuality.

Throughout the stages outlined above, family members must be reminded that they need time to themselves and moments of rest if they are to keep emotionally and physically fit. The family members providing primary care may exhibit the same symptoms of burnout discussed later in Chapter VI. Calling on friends or other relatives for assistance provides a respite from the responsibilities and worries of caring for the patient.

One final point must be made: Single adults may want to turn to their families when diagnosed:

> I think that whether you're dependent on your parents or not, when you're sick, you go to them. I was like that when I was 8. I'm like that at 18. And I'll probably be like that when I'm 28. If I get anything that exceeds the flu, I'll call home.[180]

But not everyone can return to his parents. Those who have begun or established their own lives elsewhere may need to seek local medical care to continue working, or to maintain continuity for their children. Patients in these situations require special attention from caregivers in terms of sources of emotional support and awareness of community resources.

The response of families to cancer can demonstrate qualities of love and support previously unrecognized. Family members may come to the patient's aid even though they have been separated by physical or emotional distance, as was the case of one wife who returned after a 23-year separation to care for her husband following surgery.[40]

Families can even learn and grow from the experience of cancer if they are willing to change patterns of relationships. Ben and Carol, for example, found the stress of his diagnosis extremely threatening to their marriage. Ben's role as protective head of the family was compromised by his hospitalization, and Carol's accustomed dependency produced panic in the face of her sudden responsibilities. After his recovery, they sought therapy to remodel their marriage. Six years later, Ben underwent a second cancer operation:

> His convalescence was longer and more complex but the stress each experienced was significantly reduced. The frantic, childlike wife (who had called the hospital so many times each day and in such panic 6 years before) no longer existed. The fatherlike husband (who had to quickly reassure her and immediately resume all of his prodigious responsibilities) was also greatly altered. In their places were two people devoted to one another and able to share the tasks of cancer treatment. Carol's mature tender love was a gift Ben had never imagined possible. Her support and the comfort they could now offer one another is a testament to the courage with which they faced the stress of change.[35]

VI. Coping by the Health Professional

Throughout this book, a great deal of emphasis has been placed on the role of the health professional in helping cancer patients cope with their disease, but with little attention to the emotional needs of the health professional himself. Patients and medical personnel alike tend to assume that physicians, nurses, social workers, and other caregivers are immune to the stress, anxiety, and misconception surrounding cancer. In reality, health professionals are subject to the same emotions and fears their patients experience. And they deal with those emotions and fears in much the same way: They become angry; they deny the truth; they avoid the problem. If these defense mechanisms are carried to the extreme, they can isolate the health professional from his patients and coworkers. One researcher has noted that "deep psychological isolation, the loss of ability to relate and to love, lowers the fight for health." [128] Thus, the ability of the caregiver to fight for the mental and physical health of his patients can be undermined by his beliefs and attitudes concerning cancer.

Like their patients, health professionals may view cancer as inevitably leading to death, and dealing with the cancer patient may raise serious conflicts in the caregiver's mind about death and his power to prevent it.

"Nearly every physician has a large element of the hero in his self-concept," [11] and his training has prepared him to restore health and save lives. In the case of cancer, however, the reward of a rapid and effective cure is usually lacking. Treatment can be lengthy and harsh, with no guarantee of complete success. Even if a remission is obtained, there is always the threat of recurrence. Uncertainty about the patient's recovery may awaken fears about the physician's own mortality or renew painful memories about the death of someone close to him. For instance, young physicians may painfully identify with patients near their own age, especially when their social and educational backgrounds are alike.[11] Treating a child with cancer can result in sorrow and anger if the physician has a child about the same age or if he himself had suffered a life crisis at a similar age.[11]

Feeling powerless to cure the patient, and guilty about his perceived inadequacy, the physician may lash out angrily at those around him. Physicians working with children, for example, tend to become angry with parents, whose presence they see as interfering with their treatment efforts.[11] The terminally ill patient who remains cheerful and refuses to give up hope, even when the odds against his survival have been carefully explained, often produces embarrassment, dismay, and guilt in the physician. Faced with the patient's unreality, the physician eventually becomes angry, and his guilt increases as he wonders how he could react to a dying person in such a manner.[11] When a patient dies, the physician's feeling that he has somehow failed leaves him open to severe depression, particularly if he has made an emotional investment in the patient's cure.[60] In addition, the death of a patient may intensify the physician's anger and the anger may then be inappropriately displaced to another human or circumstantial "adversary."

To spare themselves from potentially painful involvement, many physicians withdraw into the minutiae of treatment, spending as little time as possible with their patients.[20] A teaching seminar revealed that:

> The oncology fellow finds himself exceedingly uneasy with his patients, dreads encounters with them, avoids their rooms, and finds excuses to be busy with something else when they expect to see him.[11]

Denying responsibility for dealing with the patient's emotional response to the disease and its treatment, the physician may delegate the task to the psychiatrist and psychologist, people he feels have more time and training for such matters.[20] However, a pediatrician disagrees with

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this approach:

> The specialist in psychological medicine has his consultant's role to play in helping us to see unconscious and, therefore, hidden reactions. But I feel that it is the responsibility of the pediatrician, if he is to practice truly comprehensive care with children and their families, to assume the leading role in bringing himself and all other health care workers to examine, understand, and effectively use their own emotional reactions as they effect the form and content of the care that is being provided the patient and his family.[185]

Certainly his remarks could be extended to other specialties and to adult patients as well.

The problem is that physicians often spend more time trying to avoid personal and intimate issues than they would use in simply listening to their patients.[11] Underlying the physician's concern about being overwhelmed by the patient's emotional needs ("If I once let it get started, I'll never get anything else done")[11] may be his own unresolved anxiety about cancer, death, and dying. The difference between the physician who interacts well with cancer patients and the one who doesn't may lie in how well each has learned to cope with that anxiety.

According to one study, professionals with some training in treating psychological problems are better able to recognize and deal with their own feelings.[136] All too often, however, physicians do not receive that sort of training unless their specialty is psychiatry.[168]

One answer is to include courses on the principles of psychosocial intervention in the medical school curriculum.[185] But the reality of an already crowded course of study may make that solution impossible in many settings.

An alternative method is incorporation of instructional programs in the hospital setting. Aside from their teaching value, these conferences, seminars, and workshops are excellent forums for medical students and young physicians to work out their feelings about cancer.

To assist physicians in training to care for patients with life-threatening illness, one cancer research institution organized a 5-month series of weekly seminars.[127] At each session, a psychiatrist and a senior attending physician encouraged oncology fellows to discuss their patients and their own feelings toward their patients. This format was chosen as a preventive intervention point, because experience has proven that pointing out the physician's anxiety to him during a crisis in patient management raised his anxiety level even higher, often resulting in arrogant or threatening behavior. At such times, the physician himself could be considered a patient. The seminar design also ensures an honest discussion of the fellows' feelings about their patients.

A university medical center began a similar, but more patient-oriented, approach in the form of conferences for medical oncology trainees.[178] Conference matter revolves around cancer patients who, in the judgment of the students, are having difficulty adjusting to diagnosis, treatment, and course of illness. An oncology faculty member trained in psychiatry leads the conference, and the student makes a 10-minute presentation on the patient and his reasons for wanting the case discussed. Afterwards, the discussion is opened to members of the house medical staff (including those having direct responsibility for the patient). All participate in formulating recommendations and possible solutions, which are carried out by the students. The open conference, with reinforcement provided by individual followup supervision, allows students to increase their skills in managing the patient and family, as well as learn more about themselves.[178]

Even if there is not enough time, staff, or money for formal training activities, psychosocial considerations can be introduced as part of the physician's rounds in the hospital. According to one psychiatrist:

> In trying to teach liaison to pediatric house staff at the University Hospital, I have found that this simple maneuver is more effective than any other; if a psychiatrist will unbend himself and appear at 7:30 in the morning once a week or so and just walk around the ward for an hour, throwing back and forth the issues coming up with each child in the ward, more meaningful teaching transactions take place in that hour than in 10 hours of formal conference.[185]

Another physician notes that informal discussions can continue throughout the day:

> Whether it's during the working rounds or over a cup of coffee or wherever it appropriately fits into the working day, we begin talking about some of the considerations that are inevitably going to come up with Johnny B.[185]

In this way, the student or young physician has an opportunity to observe how a more experienced professional handles tense situations like diagnosis or relapse. More than likely, he will realize that some questions have no ready answers and that even his teachers are not infallible when it comes to answering them. Consequently, he can begin devising his own ways to handle difficult situations.[185]

But what about the physician who has been practicing for a number of years? How can he cope with cancer's psychosocial problems—both his and his patients'? Obviously, the house staff and referring physicians participating in the seminars and conferences discussed above benefited from the sessions as much as the students. Similar approaches might be tailored to the specific concerns of experienced physicians. In particular, senior physicians—especially those who do not routinely see cancer patients—may need to be reminded that a diagnosis of cancer can no longer be equated with death.

Implicit in that hopeful statement, however, is additional pressure and stress for the managing physician. The prevalency, increased life expectancy, and chronic nature of cancer has created an enormous workload. In addition,

> patients who are living with the disease are demanding more say in their treatment program, including the right to question protocols, to arrange treatment around their own schedules, and to stop treatment when they feel it is doing no good. This can prove to be tremendously stressful both to older physicians who are not used to having their judgments questioned and to younger resident physicians who may well be having enough difficulty with their feelings of inadequacy without having their treatment programs challenged.[224]

Treating cancer today also places severe demands on the time, emotions and skills of the physician who is not part of a health care team.[182] Without team support, the physician may feel isolated and unsure of his ability to deal with complex psychosocial issues. In some instances, the hospital staff may even desert him, as was the case with Dr. Bill, the "super-specialist," whom everyone expected to assume full responsibility for a leukemia patient and his family:

> The hospital staff, with its collective back turned in full retreat, periodically [turned] its head to cry out an entreaty to the embattled young physician to "do something"; and the lonely figure of the frightened physician [struggled] with mixed feelings of guilt because he could do nothing for his patient, irritation and anger at the patient for failing to respond to all attempts at medical and psychological care, irritation and anger at the hospital staff for leaving him alone, and resentment at his supervisor for placing him in this painful position.[185]

Physicians in this situation must look for other resources to support their efforts, even though it may be difficult to recognize personal deficiencies and to seek help from others in providing comprehensive care to the patient.[185]

This should not abrogate the physician's role in the psychosocial care of the patient. Nurses, social workers, clergy, psychologists, and psychiatrists, though, can reduce the large amounts of time required by the cancer patient and family, as well as provide an outlet for the physician to discuss psychosocial problems and seek solutions himself. Toward that end, an effective referral system is invaluable for the physician who feels pressed for time or less than expert in the psychosocial area.[224]

Watching the physical condition of a cancer patient deteriorate as a result of treatment is difficult for all caregivers, who may feel a measure of guilt because of their part in the patient's decline. They perform the surgery, administer the drugs, give the radiation therapy, and encourage the patient to continue with treatment. Intellectually, they know that treatment is necessary and represents the patient's best chance for survival. Emotionally, however, the effects of treatment may not be so easy to accept. As one surgeon candidly put it: "If I thought about what I was doing to a person, I couldn't do it. But I don't think that that is my job." [103]

Whose job is it then? According to one physician, "If we are going to prolong lives we must accept some responsibility for helping to deal with the side effects." [185] Nevertheless, the lion's share of the burden for the physical and emotional consequences of cancer treatment generally falls to the nurse:

> If our doctors had to worry about all the nausea and vomiting a drug caused, they probably would feel terrible about prescribing it. I guess that puts us right in the middle. . . . They give the drug and we stand there with the emesis basin.[103]

In carrying out the daily routine of medical care, the nurse usually sees more of the hospitalized cancer patient and is more aware of his needs than any other health professional. Shared experiences like preparing for surgery and the close attention required after it offer special opportunities for developing a positive interpersonal relationship.[105] But like physicians, nurses may avoid that relationship. They may feel guilty and inadequate because they cannot do more to help the patient get well, or because they fear they will be hurt if the patient dies. Such feelings may take the form of anger—at the patient's demands, at the patient's family, or at the patient's physician. The nurse may insist there must be a drug or treatment that will save the patient, only to become angry and frustrated when the physician or medicine in general fails to produce it.[105] Cheery assurances that everything will be all right, when both the nurse and the patient know otherwise, often mask the nurse's own insecurity and anxiety about death. Changing the subject or rushing to suddenly urgent business are similarly motivated reactions to the patient's questions about his illness and its prognosis.[20]

When the nurses in one cancer center were asked about their major difficulty in nursing, their response was: dealing with patients' feelings about illness, prognosis, and death.[224] Although these nurses were attempting to address patients' psychosocial needs, they felt unable to do so because of their perceived fear of illness and death, lack of knowledge about interpersonal relationships, and lack of communication skills.

The nurses asked for and received help to evaluate and remedy the situation. Group discussions over an 8-week period led by staff members from a nearby psychiatric institute revealed that the nurses' inability to accept and understand their own feelings led to their inability to accept and understand their patients' feelings. As communication had deteriorated, the nurses felt angry, depressed, frustrated, helpless, and hopeless.[224] Since they believed "good nurses" never have such feelings, they were reluctant to discuss them with other nurses and receive the benefit of group support. Furthermore, they disagreed in their expectations about cancer and its treatment, with opinions ranging from "Why do they bother taking treatment; they're only going to die anyway," to "Why should people be so upset just because they have cancer?"[224]

When the nurses had looked to staff physicians for support, they were frequently disappointed. If the physician failed to perform the expected magic, staff discord increased and patient care deteriorated. They were unable to understand that the powerful, competent physician had his own problems dealing with the emotional consequences of cancer.[224]

As the group sessions progressed, the nurses began to accept their own feelings and to share them with each other. As a result, they were better able to deal with the same anger, depression, frustration, hopelessness, and helplessness they encountered in their patients. Eventually, the nurses came to see that physicians are not spared these feelings either. The combination of this insight and group support allowed the nurses to depend less on the physicians and to offer their own concern and suggestions to physicians facing similar problems.

Continuing management of staff stress has been undertaken at this cancer center in the form of weekly supportive group meetings of ward personnel. Seminars, courses, and training programs focusing on psychosocial issues have also been conducted for nurses, physicians, and other health professionals. And ongoing psychiatric consultation has been made available to help the nurses with their own needs as well as their patients'.

Fortunately, the nurses in the preceding study were able to recognize their difficulty and then find the resources necessary to overcome it. Sometimes, however, nurses are unable to ask for assistance, feeling it would be admitting failure in a stressful situation. Nurses in this situation may express their needs more subtly, usually in the form of complaints about the patient, e.g., dissatisfaction with his progress, recurring reports of unsatisfactory interactions, and ambivalence about continuing to work with the patient.[95]

When the need for support is demonstrated, it is not enough to reassure the nurse that the patient is indeed difficult and that competence is not the issue. Instead, the nurse needs suggestions from her colleagues for new ways of looking at the patient, alternative solutions that might only have been gained by a more experienced colleague, and tactful suggestions about areas that might have been overlooked. Then the nurse will have expanded her repertoire of interventions, leading to a solution of the problem and restoring her sense of competence. Finally, she will realize that all caregivers at some point need help from their colleagues in dealing with patients who present difficult situations.[95]

The constant search for ways to help cancer patients and their families, the constant giving and caring with varying degrees of success, can be emotionally and physically draining for the health professional. Prompted by the never ending stream of patients who hurt in so many ways and whose needs must be met, the health professional may take on too much for too long. Despite his best intentions, he may begin to lose sight of his humanity and that of his patients; he may burn out. Displaying the attitude changes that signal burnout, a social worker reported, "I began to despise everyone and could not conceal my contempt." [136] The burnout candidate may become quick to anger, unable to hold in irritation and frustration. As part of the anger, he may become suspicious, almost paranoid, that everyone is "out to get him." At the same time, he may feel omnipotent; he's seen it all, handled it all. Consequently, he may begin to take unwarranted risks with his own life and possibly even his patients'. He may become rigid, closed to any suggestions: Change is a threat. He may become silent, feeling futile and fed up but unable to talk about it.[67] The final result is an impenetrable emotional barrier that virtually precludes any form of human caring.

The aftermath of burnout is not only harmful to patients, but to the health professional as well. Ulcers, migraine headaches, and more serious illnesses, along with drug and alcohol abuse, mental illness, and marital difficulties frequently accompany burnout. Its effects are also seen in low employee morale, high absenteeism, and high job turnover. In response to an intolerable situation, the health professional may leave the field altogether or go into an administrative position that eliminates patient contact.[137]

In caring for cancer patients, then, the question becomes how to remain remote enough to think (and function) and yet close enough so that you can relate.[85]

One way is to assume physical and emotional distance from the stressful situation. This must be handled carefully, however. Certain distancing techniques can actually contribute to burnout. For example, the health professional's emotional withdrawal might take the form of referring to his patients in medical terms, such as "the osteosarcoma down the hall," rather than by name. The patient is made to seem less human, more like an object, and thus less threatening.[136] Jokes at the patient's expense may help reduce the health professional's tension, but they also have a dehumanizing effect. And where strict adherence to hospital rules—for example, refusing the family permission to remain a few minutes beyond visiting hours—may relieve the health professional of the responsibility for unpopular decisions ("I only work here"), it denies the patient's uniquely human needs.

More acceptable strategies include lowering the patient-staff ratio, although this may not be possible in all situations. A study of burnout showed a high correspondence between emotional overload and number of cases.[136] With fewer patients to care for, the caregiver has the time for more individual attention, which in turn permits him to observe the patient at good moments instead of solely in crisis situations.

Shorter shift hours, varied assignments, and sanctioned time-outs are also helpful. Stress and negative attitudes have been found to correlate with long work hours in continuous contact with patients or clients.[136] Alternating patient care with other duties may provide a much-needed breathing space. Health professionals need to understand that, like everyone else, there are days when they are not at their best. If they can elect to take that day off and spend it doing paperwork, with the reassurance that someone else will cover their patients, they are spared the guilt produced by less acceptable escapes.

A health professional in the cancer field has to have satisfactions, rewards, and positive feedback in other areas of life to continue caring. Supervisors and administrators should encourage relationships with others outside the work setting. Additional support can come from these friendships with those outside the field, as well as from family members and spouses.[222]

Supervisors should make sure that staff members take their days off—away from the hospital. Regular vacations, long enough to provide complete rest, should be insisted on. Time off to attend conferences and workshops gives the health professional an emotional and physical break from his routine and his patients.[67]

Paradoxically, burnout often produces extreme mental exhaustion on the one hand and insomnia on the other. Physical exercise—tennis, running, cycling, swimming, any activity that is physically tiring—relieves tension and encourages sleep.

Finally, perhaps the most important factor in preventing burnout or coping with its effects is peer support. Regularly scheduled staff meetings promote a supportive environment where the health professional can air his feelings, relay lessons learned, and develop new insights to his problems. They can also be the occasion for a pat on the back as well as constructive criticism. In either case, the caregiver gains an idea of what he is doing right and where he needs improvement. But most important, he learns that his emotions are an acceptable and shared response to the pressure of caring for cancer patients.

VII. Financial Aspects

1. OVERVIEW

The economic toll of cancer—for the individual and for the nation as a whole—is devastating. Estimates for 1976 place direct medical costs at over $6 billion and total costs, including losses due to mortality and morbidity, at over $30 billion.[194]

The results of a national study of 6,332 cancer patients provide a useful benchmark for hospital expenses.[195] All patients in the study were first diagnosed in 1969 or 1970, and data were gathered from them for 2 years after diagnosis. Specific patient and disease characteristics affecting variations in expenditures were noted, including:[195]

- **Extent of Disease** — Patients with localized cancers required 22 days hospitalization at a cost of $2,018, but those with advanced cancers required 35.3 days and $3,112 in hospital payments.
- **Treatment Modality** — Average hospital payments increased as the number of medical procedures increased. Surgery alone or in combination with other medical procedures was the treatment of choice in over 70 percent of all first admissions. Among the first or second admissions involving only one procedure, payments for chemotherapy exceeded those for surgery or radiation. Again, the study did not include radiation therapy or chemotherapy administered on an outpatient basis; thus it would be incorrect to assume that radiation therapy is a less expensive treatment.
- **Age of Patient** — Older patients averaged longer stays per admission. Younger patients, although having shorter stays per admission, required more admissions, on the average, during the 2-year study period.

Data gathered from the survey showed that, in 1969, the average admission lasted 15.6 days, at a cost of $1,399, or about $90 a day. Total hospital admissions for each patient during the 2 years averaged 28.2 days, with an average payment of $2,529. It must be remembered that these figures are hospitalization expenses only and do not include physician fees or costs of treatment received on an outpatient basis.

When these figures were updated to reflect 1976 costs, the average admission jumped to $2,282.[194] And 1975 statistics from another source indicated an average hospital cost of $151 per day,[6] bringing the cost of a 28-day cancer stay to $4,228 in contrast to the $2,529 figure reported by the national survey for 1969–70.

Another perspective is offered by a 1971–72 study of 115 families with advanced cancer patients.[32] The total costs of illness—hospital, physician, and burial expenses— from onset of disease to death of patient ranged from less than $5,000 to more than $50,000, with an average cost of $21,718 per study family. The figures cannot be generalized for all cancer patients, of course, but they do indicate how great a strain may be placed on family finances.

Indirect costs of cancer include income lost because of the patient's disability. Lost earning power and productivity of the patient alone are estimated to cost the country between $15 billion and $25 billion each year.[6] In addition, income and productivity lost by family members who care for the patient should be considered, but no estimates for those costs exist at present.

Findings from a study conducted at one cancer center provide an indication of nonmedical but disease-related costs for the family of a young patient. Seventy families were asked to record weekly costs in categories exemplified by the following:[114]

(1) Food (extra food bought for patient, food eaten out, or convenience foods purchased during parent's absence);
(2) Lodging for parents during the child's hospitalization;
(3) Transportation to and from the medical center;

(4) Care of siblings during parents' absence;
(5) Clothing (extra clothing bought because of patient's weight gain or loss);
(6) Miscellaneous (including telephone calls to other family members, items necessary for the patient's comfort, and gifts for the patient and siblings).

A second component of the study was loss of pay experienced by parents due to the child's illness. When out-of-pocket expenses were combined with loss of parents' pay, more than half the families reported spending 25 percent of their weekly budget on nonmedical items.[114]

Cancer expenses for adult patients may also include costs associated with treatment at a medical center or hospital away from home, such as transportation, lodging, and other travel expenses. The problems of reemployment and higher health and life insurance premiums after treatment also contribute to the financial burden.

Caregivers perhaps can do little to alter the costs faced by patients and families, but other financial guidance can be offered. Assessing their financial situation and exploring available financial resources soon after diagnosis may eliminate the accumulation of large (and frequently unexpected) debts throughout the course of the disease. If possible, a conference between a member of the oncology staff or hospital financial office and the patient's family (and the patient, in adult cancer) should be held soon after the first admission or outpatient visit.[59] Together they can examine the patient's insurance policy to determine the exact extent of coverage. An explanation of hospital policy on payment of expenses beyond those covered by insurance also can aid financial planning.

Caregivers can give patients and families information about financial resource programs and organizations. However, in the case of national programs, benefits and eligibility requirements vary locally. Hospital departments of social service, the American Cancer Society offices, and Cancer Information Service Offices (listed in *Appendix D*) can supply information about:

- Federally sponsored programs, such as Medicaid, Medicare, Social Security Disability, Supplemental Security Income, and the Veterans' Administration;
- The American Cancer Society's national and local programs and the Leukemia Society of America, Inc.;
- Social service programs of local religious organizations, churches, and synagogues;
- Services of local clubs, civic associations, and fraternal orders;
- Army, Air Force, Marine, and Navy emergency financial aid (to retired or active duty personnel and their dependents).

2. EMPLOYABILITY

Work is more than an economic necessity for many. The role that work provides and the manner in which that role is filled are important indicators of an individual's success and ranking in society. It is a source of self-esteem—being valued by others who matter and by oneself. The self-sufficiency resulting from employment brings a sense of control over one's life and one's future. Work is a search for purpose, or as Studs Terkel says in *Working*, "a search, too, for daily meaning as well as daily bread, for recognition as well as cash."[217]

As more cancer patients continue working during treatment or return to the working world, the question of employability assumes greater importance. For the recovered cancer patient, work becomes central to rehabilitation and an affirmation of "being normal." As one patient states: "A job is more than my profession; it's my connection with life."[8]

DISCRIMINATION

Possible job discrimination against recovered cancer patients has been the subject of relatively few systematic studies. Evidence that it exists has been primarily anecdotal, with occasional reports of individual discrimination appearing in newspapers and magazines. The question is: Are these incidents truly isolated accounts, or do they indicate a more pervasive national attitude?

While no proof of job discrimination on a national level exists, a 1976 study undertaken by the California Division of the American Cancer Society examined the work experience of 130 cancer patients in that state.[8] The sample consisted of the "most employable" recovered cancer patients in the California work force; that is, "persons 25-50 years old who were working at the time of cancer diagnosis, who had at least a high school education, and worked in one of six educational groups calling for some special education or on-the-job training."[8] Additionally, cancer treatment had been undertaken during the past 5 years. If these "most employable" people suffered discrimination, it could be inferred that less qualified cancer veterans would have the same or greater difficulties.

Twenty-two percent of the study sample reported at least one job rejection because of previous cancer experience. This included recovered cancer patients currently working for their precancer employers, but seeking other jobs at the same time.[8]

California's Fair Employment Practices Act was amended in 1975 to eliminate discrimination because of a medical condition, defined as "any health impairment related to or associated with a diagnosis of cancer, for which a person has been rehabilitated or cured based on competent medical evidence."[8] Thus, the study's finding of illegal job discrimination has strong implications for states without such legislation.

Other, more subtle, work-related problems were reported by the patients in the California study, including hostility expressed by fellow workers or changes in work location apparently designed to force the recovered cancer patient to resign. Others reported lack of salary advances, reduction in health benefits, or ineligibility for newly available group life insurance.

On the positive side, more than 75 percent of the group reported salary increases and health and insurance benefits equal to those of other employees. Nearly half the study population never experienced work problems because of cancer.[8]

Discrimination also exists against recovered pediatric cancer patients, as reported by a study of 60 survivors. Forty percent of the sample believed they had experienced some form of employment discrimination because of their health history.[66]

WORK PERFORMANCE

A possible concern of employers (and perhaps an element in job discrimination) is the work performance of employees with a history of cancer. The results of studies conducted by two companies support the value of hiring recovered patients and of continuing to employ those who have been diagnosed with cancer while on the job.

The first study examined the work experiences of 74 persons with known cancer histories who were employed between 1959 and 1971.[288] Company policy was to hire recovered cancer patients who had been disease-free for 5 years, and to consider those treated more recently who showed no additional evidence of disease since treatment. More than half the employees in the study had been hired within 5 years of treatment.

As of January 1972, 55 percent of the 74 employees were still working, most of them with 1 to 5 years of service; 3 percent were on disability and 42 percent were "discontinued." The discontinued group consisted of people who left their jobs voluntarily, usually within 1 year of hiring. The company felt this indicated job dissatisfaction and concluded that the turnover rate for employees with a history of cancer was comparable to that of employees who had never had cancer.[288]

Work performance ratings for 39 members of the 74-person study population were satisfactory for the majority (85 percent). Absence records for the same group compared favorably with other employees. The study concluded that "the selective hiring of persons who have been treated for cancer, in positions for which they are physically qualified, is a sound industrial practice."[288]

In 1972, another company studied 1,346 employees with a history of cancer. Most of the cases of cancer had occurred in employees 40 years of age and older. Overall, 77 percent of the patients returned to work after absences lasting an average of 106 days. Thus, the company enjoyed the return to work of many "valued older employees."[211] It should be noted, however, that members of the study population were already employed when they became ill. The study did not address the question of hiring a cancer patient, but rather the potential work performance of a recovered patient.

VOCATIONAL REHABILITATION

The rights of cancer patients in certain work situations are protected by the Rehabilitation Act of 1973. Under the definition established by this Federal statute, a cancer patient is regarded as a handicapped individual, i.e., a person who has "any impairment which substantially limits one or more of a person's major life activities."[221]

Section 503 of the Act requires contractors and subcontractors to the Federal government holding contracts of $50,000 or more, with 50 or more employees, to prepare and maintain an affirmative action program for the handicapped.[221] Section 504 is even broader in scope and prohibits discrimination against the handicapped individual by an entity receiving financial assistance administered by the Department of Health and Human Services.[220] Thus, the Rehabilitation Act of 1973 is a potent piece of legislation toward ensuring the employability of cancer patients.[48]

A portion of a 1977 study of discrimination toward cancer patients addressed cancer patient accessibility to and use of state vocational rehabilitation agencies. Information was sought on the services used by cancer patients and what programs had been implemented or proposed in accordance with the 1973 Act.

Three findings emerged from the study:[139]

- *Cancer patients are not being made aware that they might be eligible for vocational rehabilitation services.*

Only a minority of the cancer patients surveyed (15 percent) were aware of their eligibility for such services.

- *The Vocational Rehabilitaton Act of 1973 has not had a substantial impact on the rehabilitation of cancer patients.*

Special programs for cancer patients are conducted by only five states: Delaware, Florida, Michigan, New York, and Texas. Nationwide data on cancer rehabilitants indicate that the Act has had "little impact on increasing the number of cancer patients served." [139]

- *Some medical criteria used in the evaluation of cancer patients' eligibility for vocational rehabilitation services appear unreasonable.*

Of the medical eligibility criteria provided by some agencies for the study, two states (Maryland and New Jersey) used standards felt to be "unreasonable." Maryland, for example, considered chemotherapy and radical cancer surgery forms of "unusual medical treatment." Among the cancers considered by New Jersey to carry very poor prognoses were cancers in young people (under 30 years of age) and cancers of the blood and lymphatic system—despite the recent advances medical science has made in these areas.[139]

In summary, research investigating the employment situation for recovered cancer patients and those receiving treatment while on the job is less than conclusive. Anecdotal evidence indicates job discrimination; yet patients' work performance in studies undertaken by two companies appears comparable to that of employees with no cancer health history.

Federal statutes prohibit discrimination against handicapped patients, mandate affirmative action in some circumstances, and require states to include cancer patients in vocational rehabilitation programs. Clearly, generalizations about the national outlook for patients seeking employment or retaining current jobs are not possible.

SUGGESTIONS FOR CAREGIVERS

For health caregivers, awareness of patients' and family members' reported concerns may provide direction for counseling and referral First of all, it cannot be assumed that patients usually share their employment concerns with caregivers. Less than a third of the respondents in a 1978 study of recovered cancer patients in blue collar occupations thought their physicians were aware of work-related problems.[62] While the responsibility for volunteering this information might lie with the patient, the reality of the situation may require the physician and other caregivers to take the initiative and ask about conditions at work.

Perhaps the greatest service caregivers can offer patients is interpretation of medical information that will help them understand and cope with the anticipated course of the disease.[62] With this information, patients and family members can begin to plan for the patient's return to work or search for a different job. Knowledge about the patient's projected physical capabilities helps the family to realistically gauge future work performance; e.g., reduced capacity to perform strenuous work.

An important question for some patients returning to work or those seeking new employment is whether to report the nature of their illness. These patients are faced with an ethical dilemma. If they do not tell and the concealed information is revealed later by a disability report or physical examination, their employee benefits (or their jobs) might well be jeopardized. If they do tell, they are risking refusal to be hired.[62]

Lack of [illegible] vledge about the existence, extent, and nature of job discrimination toward cancer patients makes this a difficult question for caregivers as well. If they encourage patients to tell the truth, communication from the health care institution to the employer may be helpful. Employers might be reminded that decisions about hiring "must be made on an individual basis and not governed by an arbitrary 5-year cure criterion."[45] And, as suggested by one physician, a reference and assessment by the patient's physician can help an employer understand the patient's ability to be work-able.[45]

If patients have been subjected to discrimination because of their medical histories, caregivers can suggest information and assistance from a number of sources. Union representatives, the local representative in the state legislature, as well as U.S. Senators and Representatives, may be able to offer advice on courses of action. Regional or national offices of the Rehabilitation Services Administration, the Equal Employment Opportunity Commission, the National Labor Relations Board, and the American Civil Liberties Union also can be contacted.

The Rehabilitation Act of 1973 provides legal recourse for discrimination by certain employers receiving Federal assistance. Complaints against those defined by Section 503 of the Act can be filed with the Office of Federal Contract Compliance Programs, U.S. Department of Labor. For those complaints defined in Section 504, actions can be filed with the Office of Civil Rights, Department of Health and Human Services.

Studies of recovered patients and reported instances of work problems indicate a need for helping patients deal with coworkers.[8, 62] Counseling that emphasizes interpersonal skills can assist patients to decide who, how much, and how to tell about the illness. If patients encounter avoidance or open hostility, counseling can help them understand the attitudes and manage coworkers' reactions.

Although inroads are being made in the employment and reemployment prospects of cancer patients, misconceptions and lack of knowledge on the part of employers, patients, and government agencies still exist. Inconclusive, fragmented, and scarce data make the total picture difficult to evaluate, but caregivers' active interest and assistance can influence patients' employability on an individual basis.

3. INSURABILITY

The medical expenses associated with cancer make good health coverage vital. Many patients and families are covered by private health insurance, often through the wage-earner or wage-earner's employer. Group health insurance comprises nearly 80 percent of the coverage provided by private insurance companies.[57] Further, in 1975, the amount disbursed under group policies was nearly six times that paid under individual policies.[149] Health insurance coverage in the United States is extensive; in 1975, more than 165 million people under the age of 65 were protected by one or more forms of private health insurance. Those over 65—numbering 25 million—were, of course, covered by Medicare. But over half held private policies to supplement Medicare benefits.[150]

The type of coverage enjoyed by these Americans bears closer scrutiny. Cancer can be considered a catastrophic medical expense in many cases and corresponding coverage—that is, plans having at least $10,000 in maximum benefits—is important. In 1976, some 92 million people were extended catastrophic protection under major medical plans, 41 million under Blue Cross-Blue Shield and 10 million under other arrangements, for a total of 143 million Americans insured against catastrophic illness.[150] For Americans holding such health insurance policies, the costs of cancer may be manageable.

Sanguine as this summary might appear, there still are problems—even for those having catastrophic coverage. Treatment over an extended time, repeated hospital admissions, sophisticated monitoring and diagnostic tests, chemotherapy drugs, etc., can drive the cost well over the $10,000 maximum. And the patient or his family must find a way to bear the additional cost. Further, catastrophic policy coverage may vary, based on each company's differing definitions and requirements. Few people understand the extent of their policy coverage before an illness and may be unpleasantly surprised by the costs not covered. Nevertheless, insurers and insurees agree that the patient with existing coverage at the time of diagnosis will have some financial benefit.

For the person with a history of cancer applying for new or additional insurance, there is another story. The 1977 study discussed earlier, surveyed patients and insurers to determine possible cancer-related discrimination—job, insurance, and vocational rehabilitation. More than 208 of the 940 surveyed respondents claimed instances of discrimination, 90 percent of which concerned insurance, especially regarding applications for new or additional coverage.[139] The alleged discrimination was manifested by refusal for coverage, extended waiting periods, or increased premiums.

A team of medical evaluators examined each patient's diagnosis and claim of discrimination to assess the reasonableness of the underwriting actions in light of generally accepted prognoses, and found that about one-fourth of the claims were justified. Although finding "the use of increased premiums and exclusions of coverage reasonable," the evaluators judged cancellation of insurance and refusals of applications to be "less reasonable acts." [139] The study concluded that insurance-related problems experienced by cancer patients following treatment cannot necessarily be categorized as discrimination. Conceding that patients are subject to insurance-related problems, the report emphasized that many of what are viewed by cancer patients as acts of discrimination are considered by the insurance industry to be sound business practices. The study also:[139]

- Found that insurance companies do differentiate between the seriousness of cancer types for underwriting purposes. There did appear to be a lag for underwriting policies to reflect improved mortality statistics, however.
- Considered 36 percent of the underwriting actions for *individual health insurance* to be unreasonable or possibly unreasonable.
- Concluded that insurance coverage was available for most cancer patients following treatment.

No time interval was mentioned in this finding, only that "87 percent of the 245 applicants for health insurance either obtained or could have obtained insurance." [139]

Concern over health insurance benefits can be a major factor for cancer patients considering a change in employment. The 1976 California study found that insurance

> appears to be one of the major barriers to changing jobs for both patients and their spouses. There was tremendous reluctance to give up existing coverage because of the fear of not getting adequate coverage on a new job and the waiting period for eligibility to join a new employer's health plan.[8]

This same reluctance might be true of parents of children with cancer.

Life insurance can also be a problem for the cancer patient. Again, the greatest difficulties occur in applying for a new policy. For example, some insurance companies require waiting periods of up to 10 years after treatment.

The importance of health and life insurance and the influence both have over major life decisions make a clear understanding of coverage mandatory for patients and families. Caregivers, particularly medical social workers, can clarify individual policies and help patients and families to fill out forms. Families should be encouraged to keep complete records and advised to store bills and insurance forms together for easy reference at tax time. Current records of bills and payments can be kept by listing them on a single sheet using the following suggested format:[41]

Date	*Paid*	*Bill From*
7/1/78	ch. 213	XYZ Surgery
Total Charge	*Ins. Pd.*	*We Pd.*
$408.00	$365.42	$42.28

Keeping a running account of financial transactions can simplify paperwork for a family dealing with the other complications of cancer and its treatment.

VIII. Conclusions

The source material from which much of this volume was derived is representative of the field of psychosocial issues related to cancer.[189] However, in several areas, the absence of definitive data means that guidelines for caregivers are based on patients' anecdotes, on insights gleaned from the clinical experience of other caregivers in all disciplines, and/or on descriptions of support methods and programs.

Although research into patients' adaptation to cancer and the efficacy of various support modes is vital, it must be preceded by even more basic investigation—the development of methodologies for conducting research and a means of assessing patients' behavior.

Inquiries must also be made into many aspects of the cancer experience, among them:

- How can the psychosocial adjustment of cancer patients be predicted?
- How can adjustment to the disease be measured?
- Do a general pattern of behavior or stages of response exist?
- How can patient compliance with therapy be maintained?
- What are the long-term psychosocial effects of treatment on children and adolescents?
- Does job discrimination against recovered cancer patients exist?

Cooperative efforts from the social sciences, nursing, and other medical sources would more precisely identify the difficulties faced by cancer patients and their families and develop interventions geared to improving the quality of their lives. But research takes time. What can be done now? How can we convince those affected that they are not alone with cancer?

Caregivers' attention to the psychosocial dimensions of patient care consists of several tasks:

- **Understanding and adjusting their own perceptions of cancer.** As more and more cancer patients are recovering and leading full, productive lives after their encounter with the disease, caregivers must view cancer as a chronic—not terminal—disease. The confidence caregivers gain from this perception assures patients of a rational view of cancer.
- **Knowing the fears and concerns of patients and family members.** Those who provide the medical means for saving lives can learn about the psychosocial from publications, workshops, and continuing education courses. Whether a patient's mental state influences disease outcome remains to be conclusively proven (or disproven). But an understanding of fears and concerns of patients and family members is the foundation for a mutual alliance of trust and open communication. Realizing their emotional needs and accepting the patient and family as partners in the decision-making process throughout the disease can encourage adaptation to the disease and its treatment.
- **Being aware of support alternatives.** Members of the health care team can provide a context for evaluating and recommending support alternatives, as not every health professional can be expected to offer psychosocial support to every patient. Time, expertise, and access to patients can limit caregivers' ability to offer support. Besides, no single approach is best for all patients: A self-help group may be ideal for one person, family therapy may be indicated for some, while one-to-one counseling with a psychiatrist is the preferred method for another. Varying needs and preferences require a variety of methods to choose from, so the patient can be matched with the one best suited to him. Familiarity with resources available in the health care institution and in the community enables caregivers to select and refer patients to the most effective type of support.
- **Ensuring patients of a single continuous caregiver contact.** Even with the availability of health

care team members, patients and families need one primary health professional contact. Continuity may be provided by the physician, primary care nurse, or other team member, each of whom must be attuned to the patient's emotional needs.

- **Educating patients and family members.** Providing information about the medical and non-medical aspects of the disease can reduce the fear and sense of isolation associated with cancer. Just knowing that being frightened is normal, that resenting the sick role is to be expected, that being depressed is common can relieve troubled minds. Well-informed patients and family members may be more apt to follow prescribed courses of therapy and can be knowledgeable about their care. Caregivers can and should acquaint themselves with available information materials and programs for patients and families, and recommend materials for their use.

One final aspect of the experience of cancer must be noted: Despite the stress, interpersonal difficulties, and medical problems, many patients still emerge with a positive dimension added to their lives. In fact, some view it as the beginning of a second life, one to be savored and enjoyed:

> Cancer has given me a sense of myself that I didn't have. A friend told me: "Having cancer was the best thing that ever happened to you," and my friend was right. I have been to a place where I couldn't control what happened to me, how much pain I felt, how much energy I would have. I didn't want to go there, and if I could avoid doing it again, I would. But all of us must deal with that same "emotional scar," that fear of death. I will, as we all will at some point, die. The cancer has made it easier for me to understand that life here on earth is limited and that I should make the best use of my time while I'm here.[205]

Appendix A: Support Programs

1. INTRODUCTION

Because of the tendency for people with common problems to unite for their common good, the formation of peer support groups for cancer patients is neither surprising nor new.[219] The impetus for program development often comes from patients, seeking to address peer needs unmet by the traditional system.[132] Patient-visitor programs, in which "veterans" who have adjusted to their illness are sent to visit patients still struggling with their problems, are a specific application. Some organizations, such as Reach to Recovery, train medically stable patients to make postoperative visits to those who have had similar surgery. Other programs, such as CanSurmount and TOUCH, train patients, irrespective of cancer site, to function as lay counselors. In either case, the visitor serves as a role model and provides proof of adaptation to the disease. Two conditions appear to be essential for the success of patient-visitor programs: (1) professional selection, training, and supervision of volunteers; and (2) careful coordination and cooperation with health care institutions and health professionals.

More commonly, patient support programs take the form of peer groups. The concept is beneficial to caregivers and patients alike; if applied in a hospital setting, institutions can use existing social service or nursing staff to reach more patients, and patients, in turn, have access to support both from health professionals and from those who have experienced similar problems.

Descriptions of support groups reveal that interaction with fellow patients also provides:

(1) An array of similar others from which to choose information and behavior options. Factual information, such as ways to minimize nausea from chemotherapy or how to receive disability benefits, can be shared. Learning how others have faced issues like what to tell employers or how much to tell one's children can also be very helpful to patients faced with the same decisions.[241]

(2) A place for discussing personal and stressful topics. Patients who do not wish to "burden" their families with negative feelings and patients without families can express themselves openly, release pent-up emotions, and still be accepted.[64, 165]

(3) A means of accurate attribution about what is "normal." For example, it may become evident that avoidance by friends is a consequence of the disease that has been noticed by other patients, and is not due to an individual's shortcomings.[241] On the other hand, patients may realize that some reactions are not suited to the situation, as with, for instance, those who suffer unnecessary guilt about causing their own disease.

(4) A course of action to overcome passivity. Offering assistance to another, even in the group context, reduces feelings of helplessness and maintains self-esteem. Also, by considering themselves as exemplar role models for others, patients quickly abandon the role of victim.[64]

Hospital-affiliated groups may be organized in a variety of ways—by disease site (breast or head and neck cancer patients), by treatment modality (e.g., in-hospital surgical or radiotherapy patients), or by patient age. Generally speaking, leaders are nurses or social workers, with members of the nursing and medical staffs included in planning and establishing the group. Their function is to "promote interaction, encourage acceptance and support among group members, and act as resource persons."[165]

During sessions, group leaders must tie

individual experiences into common themes for consideration by other group members. Most groups, either by intent or circumstances, also involve varying degrees of teaching and education about the disease. Further, those who have led groups recommend: (1) having two group leaders to assist each other in picking up verbal and nonverbal cues from patients, (2) having coleaders meet immediately after each session for evaluation and mutual support, and (3) eliciting regular input from patients and an objective supervisor about group operations.[165]

Although peer support groups appear to be increasing in number, few evaluations of their effectiveness are available. The results of a Canadian study comparing stress levels and degree of psychosocial adjustment between two sets of breast cancer patients are therefore worth noting.[223] All subjects were receiving radiation therapy on an outpatient basis following surgery. The first set consisted of those residing in a housing facility for out-of-town patients who participated in weekly counseling meetings, as well as informal interaction. The second set comprised local outpatients who lived at home and did not attend counseling meetings. When the results of the pre- and post-treatment adjustment measurements were compared, the first set of patients was

> significantly more apt to have talked frankly about their illness and found they received significantly more help from other patients. In addition, [they] consistently reported higher satisfaction with treatment, medical personnel, and other hospital staff.[223]

The different structures, settings, and approaches of support groups have produced individualized variations on the general theme. One hospital, for instance, formed three age-defined groups that worked with a poet from a local university. Originally intended to provide less verbal patients with a form of expression, experience proved that all patients and staff members benefited from the "Writer-in-Residence" program.[64] In fact, the group is planning to publish a book of its collected poems.

Peer support groups have certain limitations; not all patients are comfortable in a group situation nor even interacting with other patients. In institutional settings, careful attention must be given to obtaining medical sanction and to the cost of the program. In some instances, the availability of health professionals to establish, train, and supervise others in the program is limited. Yet the problems can be overcome and innovative solutions devised, as the following descriptions of successful programs testify. And the benefits to the patients can be substantial:

> Not all patients will want a group experience, but those who *do* will find a new source of emotional support to help them tolerate the uncertainty of their illness. Cancer patient groups, like other group therapies, tend to attract the verbally able, yet these patients also suffer from feelings of being isolated from others and from themselves. While nothing will replace the one-to-one relationship in providing clinical services, the group process officers a unique way of enabling cancer patients to mourn, to grieve, to express anger and doubt, to recognize themselves in others, and to experience themselves as "not alone."[64]

2. PROGRAMS FOR THE ADULT

NATIONAL

The following organizations offer assistance to patients and families on a national basis through local chapters.

Leukemia Society of America, Inc.

Financial assistance and consultation services for referrals to other means of local support are offered by chapters of the Leukemia Society of America to cancer patients with leukemia and allied disorders. Financial coverage is reserved for outpatients and pays up to $600 per patient per year of costs not covered by other sources. The program includes payment for drugs used in the care, treatment, and/or control of leukemia and allied diseases; laboratory costs associated with blood transfusion; transportation; and up to $300 of costs for x-ray therapy for early Hodgkin's disease and up to $300 of costs for cranial radiation for children with acute lymphocytic leukemia.

For more information about the program and its local chapters, contact:

Leukemia Society of America, Inc.
211 East 43rd Street
New York, New York 10017
(212) 573-8484

Make Today Count

Patients with incurable diseases and their families have formed over 200 chapters of Make Today Count, with the simple goal of "living each day as fully and completely as possible." Founded in 1973 by Orville Kelly, the organization includes, on an associate basis, cancer patients and other seriously ill people, their families, nurses, physicians, other health professionals, and any interested community members.

The organization's philosophy and goals are:

(1) To help the patient and family cope with life-threatening illnesses.

(2) To improve the quality of life for everyone with serious illnesses.

(3) To identify emotional problems of life-threatening illnesses and teach people to cope with them.

(4) To promote openness and honesty in discussing and dealing with serious illness.

(5) To assist the professional in communicating and meeting the needs of the patient, family, and friends faced with a life-threatening problem.

Make Today Count brings together cancer patients, other seriously ill people, and concerned members of the community to discuss and resolve personal and emotional problems. The organization is for emotional self-help only and does not become involved in the medical or financial aspects of cancer. Chapters are organized informally, with meetings held monthly or semimonthly. Local speakers often make presentations at the meetings.

For further information, contact:

Make Today Count
P.O. Box 303
Burlington, Iowa 52601
(319) 754-7266
(319) 754-8977

United Cancer Council, Inc.

The United Cancer Council (UCC) is a federation of voluntary cancer agencies, who seek the control of cancer through a three-point program of service, education and research. Agencies are funded through the United Way of Giving in most communities where they are located. Not all agencies are called United Cancer Council; the Dayton, Ohio Agency, for example, is the Montgomery County Society for Cancer Control.

Local agencies provide:

(1) Community cancer health services:
  - Cervical cytology screening
  - Hemoccult tests
  - Smoking withdrawal clinics
  - Breast cancer detection clinics.

(2) Direct help to cancer patients:
  - Nursing, homemaking, and housekeeping
  - Medications
  - Prostheses and rehabilitation service.

(3) Health promotion:
  - Speakers bureau
  - Film showings
  - Work with local media
  - Education workshops
  - Seminars directed toward cancer patients, physicians, nurses, therapists, social workers, clergy.

(4) Rehabilitation:
  - Programs and therapy groups for colostomy, mastectomy, and laryngectomy patients as well as family members.

For further information on this national voluntary agency, contact:

United Cancer Council, Inc.
1803 N. Meridian Street
Indianapolis, Indiana 46202
(317) 923-6490

United Ostomy Association

Although its membership is not limited to cancer patients, the United Ostomy Association (UOA) offers emotional support from others with similar problems.

This nonprofit organization comprises more than 500 chapters, representing over 36,000 members in the United States and Canada. Local chapters are made up of ostomates whose goal is providing mutual aid, moral support, and education to those who have had colostomy, ileostomy, or urostomy surgery. Although UOA is a lay organization, chapters are served by medical advisory boards consisting of general physicians, surgeons, and enterostomal therapists. With the consent of the patient's physician, trained chapter members can perform a valuable rehabilitation function by visiting homes and hospitals to offer postsurgical followup to ostomy patients Members are also eligible for the UOA insurance programs, including a hospital income plan and major medical plan.

Less tangible benefits offered by the national organization include:

- encouraging development of better equipment and supplies for ostomates;
- promotion of better management techniques;
- publishing of ostomy information (including the *Ostomy Quarterly* magazine and other publications on the care, management, and sexual aspects of ostomy);
- answering letters from ostomates in need of helpful advice;
- education at annual and regional conferences;
- public relations and publicity;
- encouragement of government legislation benefiting ostomates;
- cooperation with other health service agencies interested in ostomy rehabilitation; and
- seeking solutions to common problems.

For more information, contact:

United Ostomy Association, Inc.
1111 Wilshire Boulevard
Los Angeles, California 90017
(213) 481-2811

CanSurmount

The CanSurmount program is a "therapeutic community" composed of the patient, the family member, the CanSurmount volunteer, and the health professional. On physician referral, a trained CanSurmount volunteer, who is also a cancer patient, meets with patients and families in the hospital and home.

The goals of the CanSurmount program are:

1. To provide carefully selected and trained volunteers, who are cancer patients, to visit with other cancer patients and their families;
2. To provide continuing education and support for volunteers;
3. To provide cancer patients and their families with current information, enabling them to cope more effectively with cancer;
4. To help health professionals better understand the needs of cancer patients and their families;
5. To help the public better understand the needs of cancer patients and their families.

Volunteer training varies in different communities, but generally includes:

1. Discussion and seminars with health professionals;
2. Guidance in the art of listening;
3. Assistance for volunteers in exploring their own feelings about cancer and their involvement in the program.

In 1973, CanSurmount was begun in Denver, and by 1979 had expanded to most of the community hospitals in the Denver Metropolitan area, to six hospitals throughout the state as well as to Westchester County, New York and San Diego, California.

CanSurmount began as a program of the American Cancer Society (Colorado Division) and in 1978 was designated a national program by the American Cancer Society.

For further information contact:

American Cancer Society
777 Third Avenue
New York, New York 10017
(212) 371-2900

I Can Cope

I Can Cope addresses the educational and psychological needs of people with cancer. Developed at North Memorial Medical Center in Minneapolis, Minnesota, the course content includes:

- learning about the disease,
- learning to cope with daily health problems,
- learning to express feelings,
- learning to live with limitations, and
- learning about local resources.

Eight classes form the course, which is taught by health professionals from the hospital. The learning objectives of each session are accomplished by lectures and group discussions; study assignments are given for every class. By educating patients and their families about cancer and about methods to deal with psychological problems, the program's directors restore a sense of self-control to their patients' lives.

Under the sponsorship of the Minnesota Division of the American Cancer Society, a package of training and instructional materials has been developed. The kit contains print and audiovisual materials, including leaders' and participants' manuals, that can be used to establish the program in other settings.

I Can Cope has been designated a national program by the American Cancer Society.

For further information contact:

American Cancer Society
777 Third Avenue
New York, New York 10017
(212) 371-2900

International Association of Laryngectomees

Sponsored by the American Cancer Society, the International Association of Laryngectomees is the umbrella organization of 255 local clubs (which may have names such as Lost Chord, Anamilo, and New Voice) that promote and support the total rehabilitation of people with laryngectomies.

At the request of the physician, members who are themselves laryngectomees call on hospitalized patients to offer moral support and encouragement. If the physician desires, members make preoperative visits and offer help to the patient's family.

Other projects of this voluntary organization include:

- seminars or institutes for prospective teachers of postlaryngectomy speech,
- a national program of special education in first aid and artificial respiration for laryngectomees,
- a directory of esophageal speech instructors,
- the continuation of annual international conventions, and
- a program to inform employers about the reemployability of laryngectomees.

For more information, contact a local office of the American Cancer Society.

Reach to Recovery

The American Cancer Society's Reach to Recovery Program provides rehabilitation support for women who have had mastectomies. Designed to meet these women's physical, psychological, and cosmetic needs, the program works through a corps of carefully trained volunteers who have successfully adjusted to their own surgery.

By referral from the patient's physician, the volunteers make hospital visits a few days after surgery, bringing information about rehabilitative exercises and a temporary breast form (prosthesis). They also demonstrate the exercises and provide literature for the patient's family. Volunteers are specifically trained not to discuss medical matters with the patient.

Reach to Recovery also distributes educational materials for health professionals and will provide lectures and demonstrations at health institutions.

For more information, contact a local office of the American Cancer Society.

The American Cancer Society

The American Cancer Society (ACS) is a national voluntary organization offering programs of cancer research, education, and patient service and rehabilitation.

Local ACS units conduct service programs for cancer patients and their families, including:

- information, counseling, and guidance concerning ACS services, community health services, and other resources;
- equipment loans for care of the homebound patient;
- surgical dressings; and
- transportation to and from treatment.

Depending on the facilities and resources of the units, these programs may be expanded to include home health care, blood programs, assistance with employment problems, social work assistance, medications, and a complete rehabilitation program.

The ACS also conducts rehabilitation programs directed to the laryngectomy, mastectomy, or ostomy patient, offering psychological and physiological assistance.

For further information, consult local telephone directories for the closest ACS office or contact:

American Cancer Society
National Headquarters
777 Third Avenue
New York, New York 10017
(212) 371-2900

REGIONAL

The following programs are affiliated with local hospitals and/or offer support services to a regional constituency.

Cancer Call-PAC (People Against Cancer)

Cancer Call-PAC is an emotional support telephone service of the American Cancer Society (Illinois Division) operating 7 days a week, 24 hours a day. Calls by patients and family members are relayed to an intermediary who assesses the situation and puts callers in touch with trained patient volunteers, members of the clergy, or professional counselors.

Call-PAC volunteers are recovered cancer patients and family members who have been trained as empathetic listeners. They do not offer medical advice nor interfere with the physician-patient relationship.

The service began in the Chicago area in 1973 and has subsequently spread to other areas of Illinois served by the Illinois Cancer Council.

For further information contact:

Service and Rehabilitation Director
American Cancer Society
Illinois Division
37 South Wabash Avenue
Chicago, Illinois 60603
(312) 372-0471

UCLA Psychosocial Telephone Counseling Service

The UCLA Jonsson Comprehensive Cancer Center operates a free telephone counseling service directed to the psychosocial needs of patients and caregivers. Counseling is provided by a trained mental health professional who directly assists cancer patients, family members, and friends by phone or refers them to other professional resources. Caregivers are offered assistance in dealing with their patients or are supplied with referrals to other sources. The service is operated during business hours Monday through Friday, and callers from area codes 213, 714, and 805 can use a toll-free number (1-800-352-7422).

For further information, contact:

UCLA Jonsson Comprehensive Cancer Center
Psychosocial Counseling Service
1100 Glendon Avenue, Suite 344
Los Angeles, California 90024
(213) 824-6017

Cancer Care, Inc. of the National Cancer Foundation

Cancer Care, Inc. of the National Cancer Foundation is a voluntary social service agency which provides professional counseling and planning to advanced cancer patients and their families. Plans for care at home may include provision for nursing care, homemaker home-health aides, housekeepers, and other services. Direct services are provided primarily in the tri-state metropolitan region of New York, New Jersey, and Connecticut. The agencies collaborate with medical, health, and welfare organizations in community planning for the catastrophically ill; conduct programs of professional consultation and education, social research, public affairs, and public education on a national and worldwide basis.

For more information, contact:

Cancer Care, Inc.
One Park Avenue
New York, New York 10016
(212) 679-5700

TOUCH (Today Our Understanding of Cancer is Hope)

TOUCH is a rehabilitation service co-sponsored by the Alabama Division of the American Cancer Society and the Comprehensive Cancer Center at the University of Alabama in Birmingham. TOUCH began in July 1976 in Birmingham; chapters were subsequently established in three cities, with additional groups planned for three more areas. The program's goal is to provide assistance to the cancer patient and his family in forming realistic, positive attitudes toward cancer and its treatment.

Specifically, suggestions are offered for fulfilling work obligations, maintaining social and leisure activities, and locating and using community resources. Encouraging patients to continue prescribed treatment and avoiding unproven treatment methods are other program aims.

TOUCH offers support through trained peer counselors who contact patients and families on physician request. Counselor training consists of group instruction by physicians, seminars in counseling and visiting skills, and use of a programmed text (*Psychological Aspects of Cancer Patient Care* by Elizabeth A. Smith). Another component of the program is the monthly meeting, where patients and family members may meet for emotional support. Guest speakers chosen by group members are often invited, although time is allowed at each meeting for breaking into small groups for sharing and discussion.

For additional information, contact:

Marilyn C. Cain
Coordinator, Cancer Control Program
The University of Alabama at Birmingham
104 Old Hillman Building
University Station
Birmingham, Alabama 35294
(205) 934-2620

3. PROGRAMS FOR THE YOUNG

Candlelighters

Candlelighters is a national organization of groups for parents of children with cancer. Now numbering over 110 chapters and affiliates in 40 states, Candlelighters was formed almost simultaneously in Washington, D.C., Florida, and California in 1970. The name is taken from the saying that "it is better to light one candle than to curse the darkness." Not all groups are called Candlelighters; the Wisconsin organization, for example, is LODAT (Living One Day At a Time).

In 1976, the Candlelighters Foundation was created. Headquartered in Washington, D.C., it maintains communications between parents and professionals through quarterly newsletters and between groups through bimonthly newsletters. It publishes an annual cumulative bibliography for parents, offers information and assistance in forming new groups, and makes available a variety of handbooks to such groups.

The Metropolitan Washington Candlelighters monitors legislative activity affecting cancer research and treatment.

Family support groups under the aegis of Candlelighters have many functions:

- exchanging practical information and ways of dealing with common problems,
- providing an outlet for the frustrations of those under stress through informal self-help sessions,
- offering a social outlet for parents and siblings and reducing the sense of isolation often imposed by cancer,
- disseminating information through meetings featuring medical speakers, psychologists, insurers, etc., and
- directing families to professional counseling, if desired.

Some family groups have instituted other devices to help parents outside the group setting. Examples are a toll-free telephone hotline and a program providing parent visitors through a local hospital for the newly diagnosed family.

St. Louis Candlelighters — Cardinal Glennon Memorial Hospital

The St. Louis Candlelighters, in cooperation with Sister Margaret Weeke of Cardinal Glennon Memorial Hospital, has established five youth groups, composed of teenagers who have cancer, and siblings of cancer patients. The concept originated in 1975, when an adolescent with Hodgkin's disease, barred from attending an adult self-help group, voiced her concern to Sister Margaret.

The groups raise funds for making the clinic a more comfortable place and serve as a support organization for members. Each of the five groups has an adult sponsor. Sessions have no set agenda, but group dynamics have resulted in some interesting patterns:

- Problems with everyday aspects of life have been minimized because of the group members' ability to work out their frustrations with each other. Complaints about school, for example, all but disappeared after participants had worked within the group for a while.
- Group members find their peers a safer outlet for their frustrations than their parents, because they wish to spare their parents as much distress as possible.
- Group members are extremely supportive of new patients and help them cope with the effects of cancer both by example and by informal counseling.
- Siblings of patients attend group sessions more regularly than the patients themselves. The patients appear to value the formal group structure more as a means of establishing contact with their peers.

For more information on Candlelighters chapters and programs, contact:

Candlelighters Foundation
123 C Street, S.E.
Washington, D.C. 20003
(202) 483-9100
(202) 544-1696

Ronald McDonald Houses

The first Ronald McDonald House opened in 1974 as a place where out-of-town families can stay while their children are being treated at the Children's Hospital of Philadelphia. The House is available for families of seriously ill children and provides lodging at economical rates. Based on this model, Ronald McDonald Houses were opened in Chicago and Denver. Similar houses are planned for Atlanta, Boston, San Diego, Palo Alto, Los Angeles, New York, Washington, D.C., and Houston.

For further information about the Ronald McDonald House program, contact:

Mr. A.L. (Bud) Jones
Ronald McDonald House Coordinator
c/o Golin Communications, Inc.
500 North Michigan Avenue
Chicago, Illinois 60611
(312) 836-7100

4. HOSPICE PROGRAMS

The hospice concept is an approach to providing care for terminally ill patients and their families; it is a way of dying rather than a place to die. Central to this concept is the management of terminal disease so that patients can live comfortably until they die, that families live with them as they are dying, and that families go on living afterward. England's hospices, particularly St. Christopher's Hospice led by Dr. Cicely Saunders, are the predecessors of the United States' hospice movement. Hospice is a philosophy that emphasizes:

- help in dealing with emotional, spiritual, and medical problems;
- support for the entire family;
- keeping the patient in his home for as long as appropriate and making his remaining life as comfortable and as meaningful as possible;
- professional services from a health care team supplemented by volunteer services, as appropriate to individual circumstances; and
- relief of pain and other symptoms.

Although an important goal of the hospice concept is providing emotional support for the patient and family, the primary objective of care is comprehensive management of physical symptoms during the advanced stage of disease. Attention to symptom control, including the relief of pain, is as necessary to a dying person as emotional counseling. Anticipating pain and administering medication when needed (as opposed to timed dosages) are important to pain management for hospice patients. The goal of most programs is keeping the patient comfortable, yet alert, something often achieved by the use of narcotics.

Hospice programs are attracting interest from many communities in the United States. There are currently 41 functional programs providing care for the terminally ill, 73 provisional programs either in the planning stages or expected to be in full operation within 2 years, and 162 institutional programs affiliated with home health care programs and hospitals.

Home care programs, in which patients are referred to a central administrative office, are usually physician-directed and coordinated by a community group. Patients are referred by community physicians, hospital discharge planners, social workers, families, clergy and others. Specific policies vary among individual patients and organizations, but the Hospice of Marin in California provides a representative example of home care program.[36] On referral, staff members interview the patient and family and work with the patient's physician to establish a program of professional and volunteer assistance. Families are seen by members of a multidisciplinary team at least once a week, although their services are available 24 hours a day, 7 days a week. In addition to providing direct care, hospice nurses teach family members to care for the patient. Family counseling, including emotional and spiritual support, is a continuous occurrence bolstered by frequent telephone contact. After death, bereavement follow-up with the family is accomplished by telephone calls, visits, and monthly gatherings.

Because some hospice home care programs are limited to adult patients, a project was funded by the National Cancer Institute to study the feasibility and desirability of home care for the dying child as an alternative to final hospitalization.[134] In this project, parents became the primary caregivers, with support provided by health professionals. Preliminary results indicate that home care might be an alternative to hospitalization when certain considerations are met:[135]

(1) cure-oriented treatment has been discontinued,

(2) the child wants to be at home,

(3) the parents desire to have the child at home,

(4) the parents recognize their ability to care for their ill child,

(5) the nurse is willing to be an on-call consultant, and

(6) the child's physician is willing to be an on-call consultant.

The benefits to families wishing to participate in such a program are substantial: Caring for the child restores a sense of control and fulfillment to the parents and provides a familiar, loving environment for the child in his last days. The mother of one boy in the study, for instance, was glad her son could continue to care for his plants, which she would bring to him for daily watering. She also felt that caring for her son at home gave her a degree of control not possible in a hospital. She could supply the quiet surroundings he needed because of his sensitivity to noise: "What would have happened if he had been in the hospital? How can you stop the cleaning women from clanking their equipment?"[134]

If the child no longer needs the specialized services and facilities provided by a hospital, home care may reduce the financial burden to the family without relinquishing needed health professional assistance. For some families, home care represents a valuable option for the child dying of cancer.

Hospice projects currently funded by NCI include Riverside Hospice (Boonton, New Jersey), Hillhaven Hospice (Tucson, Arizona), and Kaiser Permanente Hospice (Norwalk, California). Each emphasizes home care with a backup of free-standing facilities and utilizes volunteers as an integral part of the program.

Hillhaven Hospice in Tucson, Arizona, was the first free-standing facility in this country. The 39-bed hospice provides a variety of amenities to its patients: round-the-clock visiting hours, a communal kitchen where patients can cook, and even Wednesday-night wine and cheese parties. Patients are encouraged to decorate and furnish their rooms with treasured possessions brought from home and to contribute to the hospice newsletter.[130] The facility is planning a home care program and expansion plans include more rooms for patients and for couples.[239]

The Riverside Hospice in New Jersey demonstrates yet another variation; it is a free-standing facility, but is legally an affiliate of Riverside Hospital. On physician referral, the hospice team works in coordination with the personal physician and others responsible for patient care.[178]

The Connecticut Hospice, Inc., in New Haven was begun in 1974 under a grant from the National Cancer Institute as a model for other communities and as a center for the teaching and study of terminal care in the United States. An inpatient facility is being built that will supplement the existing home care program with short-term admissions for symptom and pain control to relieve families from continuous home care. Long-range plans envisage a service allowing families to leave patients at the facility during working hours. The building also will house patients who have no families to care for them.[112]

The Connecticut Hospice, Inc., along with other hospice programs, has brought volunteers into the home. Volunteers can provide a badly needed respite for family members, as was the case with one exhausted wife. She could not continue her husband's round-the-clock care, yet did not wish to admit him to the hospital. Two volunteers were able to "patient sit," allowing her to rest and to make long-term arrangements for others to be with her husband at regular intervals.[111]

A combination home care/inpatient program has been developed at St. Luke's Hospital Center in New York City. Hospice team members—a medical director, clinical nurse specialists, a social worker, staff psychiatrists, an outside psychiatrist, and a chaplain—function mainly in a consulting capacity, as the patient's physician usually maintains primary care responsibility. Hospice inpatients are allowed certain exceptions to hospital regulations, such as unlimited visitors around the clock and walks on the grounds if accompanied by a hospice team member.[178]

Those wishing more specific information about hospice care might contact:

The National Hospice Organization
301 Tower Suite 506
301 Maple Avenue West
Vienna, Virginia 22180

Appendix B: A Patient's Bill of Rights

The American Hospital Association presents a Patient's Bill of Rights with the expectation that observance of these rights will contribute to more effective patient care and greater satisfaction for the patient, his physician, and the hospital organization. Further, the Association presents these rights in the expectation that they will be supported by the hospital on behalf of its patients, as an integral part of the healing process. It is recognized that a personal relationship between the physician and the patient is essential for the provision of proper medical care. The traditional physician-patient relationship takes on a new dimension when care is rendered within an organizational structure. Legal precedent has established that the institution itself also has a responsibility to the patient. It is in recognition of these factors that these rights are affirmed.

(1) The patient has the right to considerate and respectful care.

(2) The patient has the right to obtain from his physician complete current information concerning his diagnosis, treatment, and prognosis in terms the patient can be reasonably expected to understand. When it is not medically advisable to give such information to the patient, the information should be made available to the appropriate person in his behalf. He has the right to know by name the physician responsible for coordinating his care.

(3) The patient has the right to receive from his physician information necessary to give informed consent prior to the start of any procedure and/or treatment. Except in emergencies, such information for informed consent should include but not necessarily be limited to the specific procedure and/or treatment, the medically significant risks involved, and the probable duration of incapacitation. Where medically significant alternatives for care and treatment exist, or when the patient requests information concerning medical alternatives, the patient has the right to such information. The patient also has the right to know the name of the person responsible for the procedures and/or treatment.

(4) The patient has the right to refuse treatment to the extent permitted by law, and to be informed of the medical consequences of his action.

(5) The patient has the right to every consideration of his privacy concerning his own medical care program. Case discussion, consultation, examination, and treatment are confidential and should be conducted discreetly. Those not directly involved in his care must have the permission of the patient to be present.

(6) The patient has the right to expect that all communications and records pertaining to his care should be treated as confidential.

(7) The patient has the right to expect that within its capacity a hospital must make reasonable response to the request of a patient for services. The hospital must provide evaluation, service, and/or referral as indicated by the urgency of the case. When medically permissible a patient may be transferred to another facility only after he has received complete information and explanation concerning the needs for and alternatives to such a transfer. The institution to which the patient is to be transferred must first have accepted the patient for transfer.

(8) The patient has the right to obtain information as to any relationship of his hospital to other health care and educational institutions insofar as his care is concerned. The patient has the right to obtain information as to the existence of any professional relationship among individuals, by name, who are treating him.

(9) The patient has the right to be advised if the hospital proposes to engage in or perform human experimentation affecting his care or treatment. The patient has the right to refuse to participate in such research projects.

(10) The patient has the right to expect reasonable continuity of care. He has the right to know in advance what appointment times and physicians are available and where. The patient has the right to expect that the hospital will provide a mechanism whereby he is informed by his physician or a delegate of the physician of the patient's continuing health care requirements following discharge.

(11) The patient has the right to examine and receive an explanation of his bill regardless of source of payment.

(12) The patient has the right to know what hospital rules and regulations apply to his conduct as a patient.

No catalog of rights can guarantee the patient the kind of treatment he has a right to expect. A hospital has many functions to perform, including the prevention and treatment of disease, the education of both health professionals and patients, and the conduct of clinical research. All these activities must be conducted with an overriding concern for the patient, and, above all, the recognition of his dignity as a human being. Success in achieving this recognition assures success in the defense of the rights of the patient.

Approved by the House of Delegates of the American Hospital Association, February 6, 1973.

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Appendix C: Current Psychosocial Research

The National Cancer Institute operates the International Cancer Research Data Bank (ICRDB) Program, which collects and disseminates the latest cancer research information. The ICRDB product of greatest interest to readers of this volume is likely to be the *Special Listing of Current Cancer Research: Patient Care, Rehabilitation, and Psychosocial Aspects of Cancer Treatment*. This publication contains brief descriptions of nearly 400 ongoing research projects, and an index of all investigators working on these projects. The descriptions are arranged under the following headings:

- I. PSYCHOSOCIAL ASPECTS OF CANCER PATIENT CARE AND OTHER ASPECTS OF PATIENT REHABILITATION
    - A. Development of Prostheses for Cancer Patients
    - B. Patient and Family Psychological Adjustment to Death and Dying (including hospice studies)
    - C. Psychosocial Aspects of Care and Rehabilitation of Cancer Patients
    - D. Employment of Cancer Patients
    - E. Other Broad Patient Care and Rehabilitation Programs, Including Home Care Programs
- II. CARE, REHABILITATION, AND PSYCHOSOCIAL FACTORS IN SPECIFIC PATIENT POPULATIONS
    - A. Care, Rehabilitation, Psychosocial Aspects, and Broad Studies of Neoplastic Disease in Children
    - B. Psychosocial Aspects of Rehabilitation of Breast Cancer Patients
    - C. Care, Prosthetic Development, and Rehabilitation of Patients with Head and Neck Cancer
- III. EDUCATIONAL PROGRAMS IN ONCOLOGY AND REHABILITATION FOR NURSES, DENTISTS, AND ALLIED HEALTH PERSONNEL
    - A. Oncology Nursing Programs
    - B. Training Programs for Dental Personnel in Cancer Detection, Treatment, and Rehabilitation
    - C. Training of Other Therapists Involved in Cancer Patient Rehabilitation
    - D. Broad Programs in Clinical Cancer Education
- IV. OTHER SPECIFIC SUPPORTIVE CARE OF CANCER PATIENTS
    - A. Nutrition of Cancer Patients and Other Related Studies
    - B. Management of Chronic or Intractable Pain in Cancer Patients and Other Supportive Measures

Similar listings are available for other cancer research areas. Compiled from information supplied by cancer researchers in more than 60 countries around the world, each Special Listing contains 130 to 500 project descriptions. Every year, about 50 *Special Listings* are prepared for the ICRDB program by the Current Cancer Research Project Analysis Center (CCRESPAC), operated by the Smithsonian Science Information Exchange. A list of titles and ordering information can be obtained from:

National Technical Information Service (NTIS)
5285 Port Royal Road
Springfield, Virginia 22161

CANCERGRAMS

Another ICRDB product is a series of current-awareness publications called CANCERGRAMS. CANCERGRAMS on approximately 60 specific topics in cancer research are available by subscription. Each monthly CANCERGRAM provides 30 to 100 abstracts of recently published research results selected from over 3,000 biomedical journals and other sources.

For readers of this volume, the CANCERGRAM of greatest interest may well be *Rehabilitation and Supportive Care,* which covers rehabilitation medicine, cancer nursing, nutritional support, certain aspects of psychomedicine, and related efforts toward improving the quality of life of cancer patients. Subscriptions may be ordered from the National Technical Information Service at the above address ($24 per year, North American continent; $36 elsewhere). NTIS can also provide a list of all CANCERGRAM titles available.

CANCERLIT

All the abstracts listed in CANCERGRAMS can be retrieved through online searching of CANCERLIT, a data base containing more than 130,000 abstracts of published literature on all aspects of cancer. More than 3,000 biomedical and scientific journals are screened and abstracted, as well as books, technical reports, monographs, and theses. The data base is updated with approximately 35,000 abstracts per year.

Searches of CANCERLIT, tailored to the information needs of users, are performed by using typewriterlike terminals at more than 750 medical, scientific, and academic libraries and institutions throughout the world. These terminals are connected by a worldwide telecommunications network to the central computer facility at the National Library of Medicine in Bethesda, Maryland.

CANCERLIT can be searched using any word or group of words that might have appeared in the title, abstract, or index terms assigned to a document. Author names, publication years, and journal or document titles can also be used for searching the data base. Search results can be printed at remote terminals while "online" (direct connection to the computer) or printed "offline" (at the central computer) and mailed to users the next day.

CANCERLIT contains abstracts of cancer-related articles published from 1963 to date. Before 1975, only abstracts published in *Cancer Therapy Abstracts* and *Carcinogenesis Abstracts* were included in the data base. In mid-1975, coverage was expanded to include all cancer-related subject areas, as well as books, reports, proceedings of meetings, and other information sources.

Organizations already having an access code for other NLM data bases (such as MEDLINE or TOXLINE) can use this same code to access the CANCERLIT data base. Charges for searches vary. Other qualified organizations can obtain their own access codes by applying to the National Library of Medicine or to:

ICRDB Program
Office of International Affairs
National Cancer Institute
Blair Building, Room 114
8300 Colesville Road
Silver Spring, Maryland 20910

Appendix D: Telephone Information Services

The Cancer Information Service (CIS) is a toll-free telephone inquiry system that supplies information about cancer and cancer-related resources to the general public, cancer patients and their families, and health professionals. CIS is administered by the National Cancer Institute, and most CIS offices are associated with Comprehensive Cancer Centers.

A list of CIS offices by state with regional toll-free numbers follows:

ALABAMA:	1-800-292-6201
ALASKA:	1-800-638-6070
CALIFORNIA from (213, 714, and 805):	1-800-252-9066
COLORADO:	1-800-332-1850
CONNECTICUT:	1-800-922-0824
DELAWARE:	1-800-523-3586
DISTRICT OF COLUMBIA (Includes suburban Maryland and northern Virginia):	(202) 636-5700
FLORIDA:	1-800-432-5953
GEORGIA:	1-800-327-7332
HAWAII	
Oahu:	524-1234
Neighboring islands, ask operator for Enterprise 6702	
ILLINOIS:	800-972-0586
KENTUCKY:	800-432-9321
MAINE:	1-800-225-7034
MARYLAND:	800-492-1444
MASSACHUSETTS:	1-800-952-7420
MINNESOTA:	1-800-582-5262
MONTANA:	1-800-525-0231
NEW HAMPSHIRE:	1-800-225-7034
NEW JERSEY (Northern):	800-223-1000
NEW JERSEY (Southern):	800-523-3586
NEW MEXICO:	1-800-525-0231
NEW YORK CITY:	(212) 794-7982
NEW YORK STATE:	1-800-462-7255
NORTH CAROLINA:	1-800-672-0943
NORTH DAKOTA:	1-800-328-5188
OHIO:	1-800-282-6522
PENNSYLVANIA:	1-800-822-3963
SOUTH DAKOTA:	1-800-328-5188
TEXAS:	1-800-392-2040
VERMONT:	1-800-225-7034
WASHINGTON:	1-800-552-7212
WISCONSIN:	1-800-362-8038
WYOMING:	1-800-525-0231
All other areas:	800-638-6694

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